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<b>Author</b>	Sidhva, Dina P.
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**Living with HIV/AIDS:  
Turning Points, Transitions and Transformations  
in the Lives of Women  
from Bombay and Edinburgh**

**Dina P. Sidhva**

**A thesis submitted in fulfilment of the requirement of the degree of  
Doctor of Philosophy  
in Social Work  
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## DECLARATION

This work has been composed by me, and is my own work. This work has not been previously submitted for a degree or any other professional qualification to any other University. To the best of my knowledge and belief the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

**Dina P. Sidhva**  
**March 1, 2004**

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I dedicate my work to:

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## ABSTRACT

This study examines the HIV/AIDS epidemic from the perspective of those women who live with it and its sweeping consequences. The study examines the phenomenon of HIV/AIDS in two cities that have been dubbed as "AIDS capitals" because of the local prevalence of HIV/AIDS in Bombay (India) and Edinburgh (Scotland). These communities differ markedly in economic and social resources, but respondents from both communities share the burdens associated with HIV and AIDS.

Twenty-seven HIV-positive women participated in the study, fifteen in Bombay and twelve in Edinburgh. The participants completed a lengthy interview designed to elicit their recollections of their lives before infection as well as their experiences of HIV diagnosis and its aftermath. The interview encouraged the women to describe the experience from their own perspectives, with emphasis on experiences of turning points, transitions, and transformations. The study included women who had experienced varying degrees of the progression of HIV/AIDS, from those who were symptom-free to those who had developed the AIDS syndrome. Each interview was conducted in the native language of the respondent and was later transcribed and translated. Transcripts were examined for themes that recurred in the women's accounts of their experiences. These themes were then grouped logically, to form a set of assertions for each of three chronological stages—pre-diagnosis, diagnosis, and post-diagnosis.

Findings from the pre-diagnosis stage highlight the women's individual, social, and structural vulnerability to HIV/AIDS. Findings from the diagnosis stage focus on the importance of anger as an immediate reaction to the discovery of HIV infection. The findings for the post-diagnosis stage were focused on long-term adjustment to HIV/AIDS. This stage was characterized by turning points, transitions and transformation for many of the women, who were able to find acceptance and meaning in their lives. The study emphasized the importance for these women of being recognized as human beings. The value of telling their stories to a sympathetic listener was also discussed. A model of the process of change, from turning point, through transition, to ultimate transformation was proposed and discussed.

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## CHAPTER 1: INTRODUCTION

The past two decades have seen the rise of a previously unknown medical condition that has spread into a global epidemic. Twenty years after the world first became aware of HIV/AIDS; it is evident that humanity is facing a public health crisis as it tries to cope with the consequences of this disease (UNAIDS 2002a). If left to run its normal course, HIV/AIDS can cause social and economic devastation (Piot 2002). Countries that fail to bring the epidemic under control risk being engulfed in a vicious circle of decline in socio-economic conditions. HIV/AIDS has the capacity to diminish human development achievements, intensify poverty, and further hamper access to education, health care, and viable livelihoods (UNAIDS 2002a). At the same time, the social and public health conditions created by HIV/AIDS can increase the risk of new infection among the poor and disenfranchised, further spreading the epidemic.

Despite advances in treatment and detection, HIV/AIDS still poses a great global challenge. Since the first clinical evidence of HIV/AIDS was reported in 1981, more than sixty million people have been infected with the virus, of whom twenty million have died of AIDS (UNAIDS 2002b). Although HIV/AIDS affects both males and females, it is a particularly devastating illness among women in developing nations. Women account for a disproportionate number of new cases of HIV infection, and women who have contracted HIV/AIDS experience particularly devastating consequences associated with it (UNICEF 2001).

As a social worker and as a woman, I have developed a particular interest in the phenomenon of HIV/AIDS, which poses such a challenge to members of my profession. My birthplace is India, a country that has been hit particularly hard by the HIV epidemic, and I now live and study in Scotland, another country where HIV/AIDS has made its mark. At the end of 2001, an estimated 3.97 million people in India were living with HIV/AIDS, of whom 1.5 million were women in the 15-49 age group. According to the SCIEH (2002) the cumulative total of known HIV

positive persons in Scotland was 3597, of whom 2695 (75%) were male and 902 (25%) were female.

I have been involved in the field of social work for a substantial period of time, as a student, a professional social worker, and a Social Work academician. My professional experiences have exposed me to the difficult situations faced by impoverished women, particularly those in Bombay, who struggle to survive in the face of dehumanising societal structures of poverty, illness, abuse, and exploitation. Social and cultural forces have made these women particularly vulnerable to HIV/AIDS, and I have become aware of the challenges that this illness poses for impoverished women. This awareness has led me to explore the phenomenon of women and HIV/AIDS, in an attempt to conceptualise and further understand their lives.

My own experiences have pointed to the contrasts between a developed country, such as Scotland, and a developing country, such as India. Social, cultural, and economic conditions differ greatly in these two countries, both of which have been touched by the HIV/AIDS epidemic. I felt that it would be valuable to examine the impact of HIV/AIDS on women in the two contexts, to try to understand how they experienced the phenomenon of HIV/AIDS, starting with the time of diagnosis and continuing through their experience of adjusting and living with HIV/AIDS.

I also wanted to take a particular focus for my study—the perspective of the women themselves. It is easy to get caught up in statistics and generalizations when studying a global phenomenon such as HIV/AIDS, but this view, while valuable, may ignore important aspects of the epidemic. I wanted to understand the women's own perspective on HIV/AIDS. These women, many of whom are disenfranchised and ignored, have a unique perspective on the epidemic, which may provide us with valuable insights as we try to understand the illness. I also wanted my study, in some small measure, to give a voice to these women, to afford them the respect and dignity they deserve.



These elements, the phenomenon of HIV/AIDS, the role of women, the influence of socio-economic and cultural context, and the women's own perspective, have come together in my study. My study aims at deepening our knowledge of the life experiences, the subjective understandings of meaning, and the processes of personal change and development of women living with HIV/AIDS, by examining the turning points, transitions and transformations they face along the trajectory of their lives.

## HIV/AIDS and the Field of Social Work

Social Work is a contextual, relational, supportive activity that values the inherent worth, dignity and uniqueness of individuals (CCETSW 1995). The International Federation of Social Workers (IFSW) (2000) defines social work as a profession that:

***“promotes social change, problem solving in human relationships, and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work.”***

Thus the role of Social Work is to improve the human condition, by focussing on the needs and empowerment of persons who are vulnerable and oppressed in society. HIV/AIDS, with its tendency to infect the most vulnerable people in society and to increase their vulnerability, presents particular challenges for the field of Social Work.

Social workers often find themselves on the “front line” in dealing with social problems. In medical settings, they provide counselling to help people cope with the immediate impact of diagnosis and the consequences of illness. In community settings, they help people discover and utilise resources for dealing with a variety of problems, such as unemployment, poverty, and victimisation. In larger political settings, they may serve as advocates for people who would otherwise not have a



voice. Moreover, in the UK (although not in India) social work practice and the delivery of social services are bound by statutory responsibilities to protect vulnerable individuals and ensure that their social care needs are met. In all these capacities, social workers are likely to encounter HIV/AIDS.

Globally, HIV/AIDS has found immense opportunities to thrive among tragic human conditions fostered by poverty, abuse, violence, prejudice, and ignorance. These are the very conditions that social workers often must address. Social and economic circumstances foster vulnerability to HIV/AIDS infection and intensify its impact, while HIV/AIDS creates and intensifies the very conditions that enable the epidemic to flourish. Just as the virus depletes the human body of its natural defences, HIV/AIDS can also diminish the assets and social structures of families and communities, which are essential for successful prevention of the disease and provision of care for persons living with HIV/AIDS (Lyons 1998). It is important for Social Work as a field to understand these realities, so that those who work in the field can function most effectively. Social Work, with its emphasis on democratic and humanistic traditions, can play a central role in developing a deeper insight into the lives of those persons who are infected and affected by HIV/AIDS.

Women living with HIV/AIDS are a section of society's most vulnerable and oppressed around the world (UNAIDS 2002a). Their physiological risk of HIV/AIDS infection is compounded by low education, poor employment opportunities, and socio-cultural norms and structures of oppression that discriminate against them because of their social class or the activities they may engage in, such as sex work and drug use (UNAIDS 1999). Therefore, focusing on these women seems eminently appropriate to the field of Social Work.

## Contribution to Theory and Practice

This study contributes to our understanding of the experience of “living with HIV/AIDS”, by providing an examination of the phenomenon of change in the lives of 27 women, from two varying socio-cultural contexts, who are experiencing the virus firsthand. The study makes a connection between three somewhat abstract and overlapping concepts of turning points, transitions and transformations, and it proposes a model using these change concepts to describe the change that occurred in the lives of these women. The study provides an understanding about how HIV/AIDS affects women from diverse cultures, with diverse life histories, and it explores how the prevailing social realities of that culture impinge on their life experiences and the journeys they make with HIV/AIDS.

The study contributes to the practice of Social Work in the field of HIV/AIDS by highlighting the voices of HIV positive women and providing insight into the experiences of these women living with the illness, as well as their perspectives on the ways that HIV changed their understandings of themselves. The study informs professionals in the words of the positive women, such that they are assisted in the task of empowering women to live with this disease. Moreover, the study provides hope, insight, and meaning for persons with HIV/AIDS, their families, friends, and other persons interested in the subject.

This study also provides a place where the voices of voiceless positive women (Seshu and Csete 2002) are communicated and “heard more loudly” (Barlow 1992). This is crucial if the language of discourse about HIV/AIDS is to be changed, so that the subdued yet insistent voices of women living with HIV/AIDS are to be heard (Coovadia 1997) above the “deafening silence” (Cameron 2000) of this epidemic. It is hoped that providing a place to speak will allow the voices of these women to have an impact—to shape policy and program responses to this complex phenomenon.

## Conclusion

By portraying the experiences of respondents, this study seeks to uncover the turning points, transitions and transformations in the lives of women living with HIV/AIDS. It also seeks to understand, from the distinct perspective of the women themselves, how they lived with the changes brought by HIV/AIDS in their lives.

There are nine chapters in this study. Chapter One outlines and introduces the study. Chapter Two provides a Review of the Literature. Chapter Three describes the several methodological considerations of the study. Chapter Four portrays the accounts of the individual respondents in Bombay and Edinburgh through case summaries; also, the patterns of demographic and biographical information that emerged from the women's accounts are discussed in relation to existing data about HIV/AIDS. Chapters Five, Six, and Seven discuss the substantive findings that emerged from the lives of the respondents during the three stages that marked the progression of HIV/AIDS: pre-diagnosis, diagnosis, and post diagnosis respectively. Chapter Eight draws on the three aspects of change: turning points, transitions, and transformations, to understand the phenomenon of change and critical events in the lives of positive women. It proposes a model that facilitates an understanding of how my respondents dealt with great adversity in their lives. Chapter Nine concludes with the implications for the study and for future research, and the limitations of the study. The study is brought to a close with some final observations that emerged from the process of researching the lives of women with HIV/AIDS in Bombay and Edinburgh.

## CHAPTER 2: REVIEW OF LITERATURE

### Introduction

The first chapter introduced the subject of this study and its importance. This chapter reviews the theoretical and empirical literature that serves as the context for the study. After a section that provides an overview of the HIV/AIDS epidemic, the chapter discusses relevant issues for the three chronological stages included in this study: pre-diagnosis, diagnosis, and post-diagnosis. For each of these three stages, key issues are identified and the relevant theoretical and empirical literature is discussed. The chapter concludes with a summary. The literature that informed this chapter was drawn from the fields of anthropology, psychology, psychiatry, human rights, social work, and sociology and from the written accounts of persons living with HIV/AIDS and persons working in the field of HIV/AIDS.

### The HIV/AIDS Epidemic: A General Overview

This section will describe the HIV/AIDS epidemic, with a particular focus on India and Scotland, and on the relationships among gender, poverty, and HIV infection. Background information on the definition and progression of HIV/AIDS will not be included here; however, Appendix A does contain this information.

At the end of 2001, an estimated 40 million people were thought to be living with HIV/AIDS, of whom 37.1 million were adults, 18.5 million of them women. The number of people newly infected with HIV in 2001 was estimated to be 4.2 million adults, of whom 2 million were women. Three million people died of AIDS in 2001, and 1.1 million of these were women (UNAIDS 2002e).

The HIV/AIDS epidemic has spread throughout the world's population, including more than 190 countries on every continent of the world (Mertens and Low-Beer

1996). This epidemic has proved that we live in a truly global village. The rapid changes that are taking place in the world today have a profound impact on our lives: what happens in one place affects people all over the world (Rafei 2001).

The vast majority (95%) of people infected with HIV/AIDS today live in developing countries (The Population Council and International Family Health 2001). HIV/AIDS spreads readily in areas of urban poverty, poor health care, and social disintegration, and in areas where social and health problems already exist, making the problem of HIV/AIDS in developing countries even more complex (Miller and Rockwell 1988).

### **HIV/AIDS in India and Scotland**

Globally, India has the second highest estimated number of infections, next only to South Africa (Larson and Narain 2001). India is proving to be a fertile ground for the spreading of HIV/AIDS, given its poor healthcare system, virtual lack of public hygiene, and poor literacy rate (Jit 1999). The epidemic is virtually out of control in parts of India, where access to antiretroviral therapy is unaffordable except by a tiny percent of persons (WHO 1997). The predominant mode of transmission in India is heterosexual contact. Infection is currently concentrated among poor, marginalized groups, including sex workers and truck drivers; however, it is spreading from these groups into the larger society.

One key element in the spread of HIV in India is the sex trade. Prostitution in India is very profitable; however, the women involved are paid paltry sums and have little or no freedom to move out of the trade. Some women, driven by extreme poverty, migrate from rural areas to urban cities to work as prostitutes, and it is there that the problem is most severe (Burns 1996; Narain et al. 1994).

In rural areas, whole villages are often devoted to prostitution. These areas are usually on the routes of the hundreds of trucks that drive goods all around the country. Often times, the people inhabiting these villages and exchanging sex for money know nothing about HIV/AIDS (McDonald 1992; Pais 1996). Truck drivers

who frequent the prostitutes in these villages serve as the next step in the transmission of HIV (Burns 1996; Mane and Maitra 1992; McDonald 1992; Narain et al. 1994). These drivers often have low socio-economic and educational levels, move along the country's 20,000 miles of truck routes, and stay away from home for several weeks at a time. Although they may have sex several times a day with known prostitutes, truckers rarely use condoms. Once they are infected with HIV, truck drivers become participants in the spread of the disease, bringing it home to their wives and sometimes to their unborn children (Burns 1996; McDonald 1992; Narain et al. 1994). HIV/AIDS appears to have moved into the homes of Indians in low-risk groups—the general population (Burns 1996; Mane and Maitra 1992; Pais 1996).

Until very recently, infected blood was another major means of HIV transmission in India. As voluntary blood donation is difficult to obtain for cultural reasons, professional blood donors donate up to 50% of the blood required in the country (Burns 1996; Narain et al. 1994; Pais 1996). Surveys show that these blood donors are usually poor, illiterate, single, migrant, or unemployed men who engage in commercial sex (Burns 1996; Pais 1996). Donors would get infected either through their frequent contact with sex workers or from contaminated needles used when donating blood (Imam 1992). In turn they would infect the blood supply. Recently, strict laws and rules have provided for mandatory licensing of blood banks, a ban on professional blood donation, and strict guidelines for holding of blood donation camps. The blood banks are now required to acquire a manufacturing license to provide services (NACO 2002). These changes should reduce the spread of HIV through the blood supply.

The HIV/AIDS epidemic in Scotland and in the United Kingdom more generally has followed a very different course. As with many Western nations, HIV/AIDS was initially found mostly in gay men. The epidemic soon spread to injecting drug users, however, and it eventually spread to their sex partners as well. Drug use has been a significant factor in the spread of HIV in Scotland, and particularly in Edinburgh (Robertson 1990). Injecting drug use in Edinburgh increased rapidly in the mid 1980s, at a time when HIV was entering the population, and the practices of injecting



drug users served to spread the virus. According to Thomas (1990), Edinburgh had the unenviable position of having the highest proportion of sero-positive injecting drug users in Britain. Thus, Edinburgh has come to be known as the AIDS capital of Europe (Richardson and Gaskell 1989; Des Jarlais and Case 1992).

According to the Public Health Laboratory Service, UK (2002) the number of heterosexually acquired HIV infections diagnosed in the UK has risen significantly since 1985. The increase since 1996 has been particularly noticeable. As a result, since 1999 there have been more diagnoses of heterosexually acquired infection than of infections acquired through sex between men. Over 80% of those diagnosed in the UK who have become infected heterosexually are recorded as having acquired infection abroad. Of these, only seven percent were infected by a "high risk" partner (a bisexual man, an injecting drug user, or someone infected through blood transfusion). With the increase in the figures of those who acquired their infections heterosexually, there has been an increase in the numbers of women diagnosed.

The course of HIV/AIDS is also quite different in Scotland and the UK than it is in India. In India, effective treatments are beyond the reach of most people who are infected with HIV, and many people who contract HIV tend to develop AIDS and eventually die. In contrast, in the UK new treatments have slowed the progression of HIV to AIDS, and from AIDS to death. As a result, AIDS cases and deaths have dropped dramatically in the UK, and more people with HIV are living healthier and longer lives (THT 2002). Despite this success in containing and treating HIV/AIDS, Britain has, in the year 2001, recorded its highest annual HIV/AIDS infection increase (14 per cent) since the epidemic began (Braid 2001).

### **The Developmental Impact of HIV/AIDS**

The HIV/AIDS epidemic has provoked a developmental crisis in major regions of the world (Barnett and Whiteside 1999; UNAIDS 2002c). Globally, HIV/AIDS is best regarded as a disease of development and under-development (Schoepf 1993). Poverty, malnourishment, inadequate health care, low respect of human rights, lack

of education, poor housing, exploitation, and discrimination of women, as well as an insensitive political system all heighten the impact of HIV/AIDS on society (Moerkerk 1992). Conversely, these facets of underdevelopment—hunger, malnutrition, poverty, lack of hygiene and sanitation, natural calamities and internal strife—reduce the visibility of the AIDS pandemic (Paicheler 1992).

Throughout the world, but particularly in what is termed the "Third World," poverty and other social forces cause much human suffering. The rapid spread of HIV/AIDS, especially, in the developing nations, is inextricably woven with poverty and powerlessness (Farmer 1992). With non-sterile needles and contaminated blood playing a minor role, HIV transmission is mainly through heterosexual marital or sex with a sex worker, which, for most women in this context, is a reflection of powerlessness.

The AIDS epidemic undermines significant improvements in health indicators, and aggravates prevailing economic problems (Biggar 1988; Hankins 1997). HIV/AIDS has the potential of threatening one of the most important Third World achievements: the reduction of disease. The AIDS pandemic not only threatens to retard the process, but to completely reverse it if life expectancy rates begin to fall. AIDS tends to affect young and middle-aged adults, in their most productive years, leaving behind a population who is less capable of contending with difficulties. Improvement in the socio-economic conditions of people's lives reduces their vulnerability to the disease (Panos Dossier 1992; Moerkerk 1992). Thus HIV undermines earlier progress and reinforces some of the worst facets of underdevelopment (Moerkerk 1992).

Madavo (1998) lists five reasons why HIV/AIDS is a development issue. First, the HIV/AIDS epidemic is turning back the clock on development, especially in the developing world, where it is cutting down and impoverishing life and vital human investments. Second, it is a development issue because at the household level, it hits families where it hurts most: women and men in their most productive years. Third, HIV/AIDS and poverty together create a vicious circle: HIV thrives on poverty, while deepening it. Thus, countries that are the poorest are more unequally hit by the



epidemic. Fourth, HIV/AIDS forces countries to make tragic choices between health and the dozens of other vital investments for development. Finally, labour migration, urbanization, and cultural changes, all factors of development itself, contribute to the spread of HIV/AIDS.

Decosas (1996) suggests that HIV/AIDS is an important piece in the puzzle of international development, because it will deepen the poverty of some groups or areas and widen the gender gap in development. Further, he points out that it is “linked to all the other pieces by a labyrinth of causal pathways. It is an indicator of uneven or dysfunctional social development; it is the cause of developmental delays; and it is the result of inadequacies in the development of social and health services” (p.1).

### **HIV/AIDS and Stigmatisation**

Illnesses can be seen as metaphors, because they absorb and exude the personalities and social conditions of those who experience them. However, few illness metaphors carry the deep social and cultural meaning that HIV/AIDS does (Farmer and Kleinman 1989; Nelkin et al 1991). HIV/AIDS is socially constructed as a deadly disease that is the result of engaging in stigmatised behaviour, the deliberate violation of social norms, or a deviation from conventionally held values of ideal behaviour (Solomon 1988). Societal responses to the epidemic and to persons with HIV/AIDS are often based on archaic metaphorical concepts of fear and contagion, rather than the realities of the biological organism (Rushing 1995).

Sontag (1978) observes that these metaphors isolate and estrange people, causing pointless misery because of the meaning attributed to their illness by society. Sontag (1989) suggests that AIDS brings together two powerful metaphors about illness: first, HIV/AIDS as an invader, or an enemy that invades and destroys from within. Second, because HIV/AIDS is sexually transmitted, it also evokes the theme of plague-as-a-punishment. Moreover, Sontag (1989) suggests that the sensitivities of each era favour a certain disease. HIV/AIDS, with its linkage to blood, sex, and drugs, along with its complicated evolution and strategy to multiply itself, aptly

expresses many of the fears of our age, and as a consequence, those living with HIV/AIDS often face severe discrimination and stigmatisation.

### **The Paradoxes of the HIV/AIDS Epidemic**

The AIDS pandemic is marked by curious paradoxes and ironies. HIV/AIDS, like many other major happenings in the world today, creates numerous paradoxes (Teguis and Ahmed 1992). For example, AIDS prompts very brave and generous acts, yet it also provokes very mean-spirited and non-rational behaviour (Fineberg 1988); it leads to acts of painful discrimination on the one hand, and unconditional solidarity and support on the other (Kubler-Ross 1987). The AIDS pandemic has provided a global stage for compassion and concentrated effort to treat and cure on the one hand, and at the same time prompted fear, anger, and anxiety towards persons living with HIV/AIDS (Prewitt 1988). People all over the world share the hard commonalties of HIV/AIDS: pain, rejection, fear, dehumanisation, death and dying, as well as many losses: loss of personhood, dignity, self-esteem, love, respect, family, and friends. But they also share the many soothing, life-giving commonalties of love, loyalty, friendship, support, dignity, and hope (Altman 1986, Shilts 1987).

Paradoxes also abound in the biological realities of HIV. AIDS, perhaps the most feared epidemic in modern history, is due to a virus that is not particularly infectious. Furthermore, the disease progresses faster than most diseases, yet the incubation period may last up to 10 years and the 'window period' for developing antibodies may elude an individual from six weeks to six months (Canadian Medical Association 1993). Additionally, although the HIV does not kill, it destroys the body's defences, and allows other infections to kill it (Barnett and Blaikie 1992). Moreover, in an era of high technical competence, treatment for a microscopic, mutable, fragile virus that cannot live outside the body for long still eludes science.

Other paradoxes reflect the inequalities in the treatment and prevention of this disease. While fresh scientific efforts have resulted in a series of discoveries and advances in the understanding and control of HIV, this progress has had limited impact on the majority of persons living with HIV/AIDS, those in developing

countries who are most greatly in need of it (Lyons 1998, Cameron 2000). Ironically, this is not because the drugs are prohibitively costly to produce, but because drug-pricing structures imposed by the manufacturers make the drugs excessively high-priced, and the international patent and trade regime seeks to strangle off any large-scale attempt to produce and market the drugs at affordable levels (Angelle 2000). Although HIV/AIDS strikes the poor and disadvantaged, it also affects the highly skilled, trained, and educated. Thus not only does it hamper development, but also reverses it, and widens the gap between the rich and the poor (UNESCO 2001).

### **The Pre-Diagnosis Issue: Vulnerability**

The study is described in the three stages that mark the progress of the illness: the pre-diagnosis stage, the diagnosis stage and the post-diagnosis stage. These stages were chosen as logical time periods to examine, because each stage is characterized by particular experiences, challenges, and issues that the participants must face as they deal with the reality of HIV in their lives.

In my study, the pre-diagnosis stage covers the time that leads up to the discovery of HIV infection for each of my respondents. In examining this time period, the key question that arises, concerns the circumstances that led to each woman becoming infected with HIV: “Why or how did this woman become infected?” This question frames the issue for this stage as one of vulnerability. In the sections that follow, I will first describe the concept of vulnerability, and then go on to talk about the vulnerability of women in the context of the HIV/AIDS epidemic. Vulnerability can be considered at the individual level, the social level, and the structural level, and each of these levels will be considered in turn.

#### **The Concept of Vulnerability**

The term vulnerability is used in varied contexts, for example in medical and biophysical sciences; however, it is increasingly being studied through the lens of the

social sciences (Chambers 1989; Watts and Bohle 1993; Blaikie et al. 1994; Kaspersen et al. 1995). In the literature the definitions of vulnerability are imprecise. Identifying and capturing the meaning of vulnerability is difficult (Vogel 1997). In general however, the literature states that individuals or groups are considered vulnerable if they are predisposed to illness, harm, or some negative outcome. This predisposition can be genetic, biological, or psychosocial.

According to the United Nations (2001), vulnerability is a state of high exposure to risks, combined with a reduced ability to protect oneself against those risks and their negative consequences. Vulnerability is a part of the human condition, regardless of geography, social structures, or political and economic systems. Risk factors are unevenly distributed among the general population, and they include characteristics such as socio-demographic characteristics, economic status, physical or mental condition, age, and lifestyle. Vulnerability is both dynamic and relative, because it changes over time and across space and is multi-dimensional. Persons who are vulnerable are more likely to be victimized than those who are less vulnerable. Moreover, their state of mind makes them more fearful of victimization and its consequences, and greater vulnerability leads to stronger and more serious impact when people are victimised.

Further, the United Nations (2001) states that vulnerability and disadvantage are often used interchangeably, however, they are distinct. Disadvantage occurs when a structural or societal obstacle inhibits access to resources, benefits and opportunities. These obstacles develop from the relationships of power and the comparative worth which society gives to each group. The effects for any one group may vary depending on the societal circumstances; however, in all cases it results in an increased vulnerability to poverty, oppression, and exploitation. Disadvantages can also compound other vulnerabilities, where they exist. The structural sources of disadvantage and vulnerability comprise race, ethnicity, gender, religion, and socio-economic status.

The concept of vulnerability has only recently been applied to the HIV/AIDS epidemic (Werneck 2001). Women are vulnerable because the HIV/AIDS epidemic has deep roots in women's issues (UNIFEM 2001). They face greater dangers not only biologically, but also psychologically, socially, and structurally as well. Their vulnerability is reflected in social and cultural inequality, economic marginality, and social structures that discriminate against them and deprive them of their basic rights (deBruyn et al 1995; Kiragu 1995) across their life cycle (Women's Unit 2000). Socio-economic circumstances add to the vulnerability of individuals to HIV/AIDS and increase its impact while generating and intensifying the same conditions that enable the epidemic to thrive (Lyons 1998).

Vulnerability lies in a multifaceted interaction of environment, behaviour, and socio-medical factors such as poverty, discrimination, gender inequality, and religious, medical, and social practices (van der Vliet 1996a) and is the converse of empowerment (Mann et al 1992). Women in third world countries are among the poorest and the most vulnerable individuals (van der Vliet 1996b). Chatterjee (1990) demonstrates that vulnerability of women in India is closely linked to their lack of access to health care.

Vulnerability to HIV/AIDS can thus be considered on three interdependent levels, the individual, the social, and the structural. Individual vulnerability focuses on the various factors in an individual's development or environment that leave him/her more or less vulnerable, for instance, physical characteristics, mental development, knowledge and awareness, behavioural characteristics, personal history, life skills, and interpersonal relations. Social vulnerability to HIV/AIDS focuses on the social traditions and conditions that contribute to the risk of infection. These include prevalent customs and beliefs, subcultures and lifestyles, and economic and educational disadvantages. Structural vulnerability focuses on the inequalities in power that limit the individual's ability to make choices regarding circumstances and behaviour that may put them at risk for infection. Structural vulnerabilities include discrimination, stigmatisation, and marginalisation of particular groups in society based on factors such as gender, race, or cultural background.

## **Individual Vulnerability**

**Physiological factors.** Biologically, women are at a far greater risk than men for acquiring the disease through heterosexual contact, because during sexual intercourse a larger mucosal surface is exposed, and semen has a greater concentration of the virus than vaginal fluid (Bailey 1997; Doyal et al. 1994; Doyal 1995; Polineni 1996). The age group of women at risk is between 15 and 45, when the woman is in the child bearing and sexually active stage of her life (Mwale and Burnard 1992). Men appear to pass HIV more efficiently than women during unprotected sex, making women twice as likely to be infected by men than men are to be infected by women (Johnson and Laga 1988; Crystal and Sambamoorthi 1996). Doyal (1995) identifies some of the other biological risks for women. The internal placement of women's genital organs makes it difficult to diagnose gynaecological ailments. Therefore, infections are not easily identifiable unless external symptoms develop, thereby increasing the risk of HIV. Menstruation and metabolic changes during puberty and menopause can accentuate risk in women. Finally, childbirth could require blood transfusions, which could increase the risk of infection in women if the blood has not been properly screened.

**Psychological Factors.** Psychological factors that influence a woman's risk of becoming infected with HIV encompass a variety of circumstances. These include the woman's personality and emotional makeup. In order to protect themselves from HIV infection, women must possess knowledge about the risks and about appropriate means for protecting themselves. Beyond this knowledge, they must also possess the will and the ability to engage in the necessary self-protective behaviours. Conditions that interfere with a woman's sense of herself or with her overall emotional functioning may impair her self-protective behaviours and elevate her risk of infection.

Although there is no clear evidence about the relationship between stress and HIV/AIDS, one factor that seems particularly important for a woman's psychological functioning is her overall exposure to stress, and particularly to traumatic stress. Prolonged exposure to traumatic stress is known to weaken the immune response, but



it might also weaken a woman's psychological functioning such that she is less capable of protecting herself. Thus, the notion of trauma and of traumatic stress will be explored more fully.

The word "trauma" in every day language is generally considered to mean a highly stressful event. Pearlman and Saakvitne (1995) define psychological trauma as an unique individual experience of an event or enduring conditions, in which an individual's ability to integrate his or her emotional experience is overwhelmed or when the individual subjectively experiences a threat to life, bodily integrity, or sanity. Thus, a traumatic event or situation creates psychological trauma when it overwhelms the individual's perceived ability to cope. Allen (1995) points out that there are two components to a traumatic experience: the objective and the subjective. He suggests that the subjective experience of the objective events constitutes the trauma. Therefore the more endangered an individual feels the more traumatized the individual will be. Therefore, Giller (1995) suggests that trauma is defined by the experience of the person who lives through the trauma.

Giller (1995) makes a further distinction between Natural and Human Made Trauma. She points out that Human-Made Trauma is violence, which take the forms of war and political violence, human rights abuses (such as kidnapping and torture), criminal violence, accidents, rape, domestic abuse and sexual abuse (which includes trafficking in women). She argues that prolonged stressors, deliberately inflicted by people, are far harder to bear than accidents or natural disasters.

In the lives of women, violence is an all too frequent source of trauma. The literature points out that women are at greater risk of violence in their own homes in the private sphere than they are in the public sphere (Stanko 1985; Hanmer and Maynard 1987; Radford and Russell 1992). Hoigard and Finstad (1992) propose that women who are exposed to a great deal of violence become socialized to accept it as part of their lives. Further, violence against women is sometimes socially condoned by the media portrayals of women as objects of sex or victims of abuse (de Bruyn et al. 1995; George and Jaswal 1995).

The experience of traumatic events often produces characteristic reactions, which the clinical literature characterizes as stress-related disorders. Although many physiological and psychological disorders are attributed at least partly to stress in general, two particular psychological disorders are uniquely associated with traumatic stress. The first, Acute Stress Disorder, reflects a relatively immediate reaction to a traumatic experience. The second, Post Traumatic Stress Disorder, reflects a long-term reaction and/or sexual abuse, domestic violence, or severe chronic illness such as HIV/AIDS (American Psychiatric Association 1994).

Immediately after experiencing a traumatic event, people often cannot remember significant parts of what happened, yet may be plagued by fragments of memories that return in physical and psychological flashbacks. Nightmares of the trauma are common, as are depression, irritability; sleep disturbance, dissociation, and feeling jumpy. These reactions may fit the diagnosis of acute stress disorder (ASD). ASD describes experiences of dissociation (e.g., feelings of unreality or disconnection), intrusive thoughts and images, efforts to avoid reminders of the traumatic experiences, and anxiety that may occur in the month following the event. When these experiences last more than a month, they are described by the diagnosis of post-traumatic stress disorder (Kaplan and Saddock 1985).

The term Post Traumatic Stress Disorder (PTSD) was recognised as a formal diagnosis in the psychiatric nomenclature, when it first appeared in 1980, in the third edition of DSM-III (Kaplan and Saddock 1985). Since then it has produced a vast literature on the treatment of victims of many different sorts of trauma, as well as scientific investigations about the ways in which people react to overwhelming experiences (van der Kolk et al. 1996). The diagnosis was updated in 1994 in the latest edition, DSM-IV (Kinchin 2001). The fourth edition of the American Psychiatric Association's Diagnostic and Statistical Manual, DSM-IV, points out that PTSD is a natural emotional reaction to a deeply shocking and disturbing experience. It is a normal reaction to an abnormal situation. PTSD is a serious and debilitating illness that follows exposure to trauma. It can result from a single traumatic event, such as a rape, or an ongoing pattern of traumatic experiences, such as physical



and/or sexual abuse, domestic violence, or severe chronic illness such as HIV/AIDS (American Psychiatric Association 1994).

The literature suggests that the psychological effects of PTSD may manifest themselves in increased risk-taking behaviour, such as substance use, poor eating habits, or unsafe sexual activity. Further, the pervasive impact of trauma results in a range of psychiatric disorders that overlap (van der Kolk and McFarlane 1996), among which are often problems with substance abuse (Wolfe and Kimmerling 1997). In their study on “violence, trauma and post-traumatic stress disorder among women drug users”, Fullilove et al. (1993) suggested that PTSD might account for high sexual risk-taking activities among female crack users. Studies have found that women with histories of psychological trauma (including post-traumatic stress, dissociation, and other psychiatric disorders linked to psychological trauma) often develop alcohol and drug abuse (Najavits et al. 1997). They point out that epidemiological studies have found higher rates of PTSD among women than men. Further they have found higher rates among substance abusers than the general population. Therefore, women who abuse drugs are more likely to have PTSD than women in the general population. Taken together, these findings indicate that women substance abusers are more likely to suffer from PTSD. Vice versa, women with PTSD are more likely to be substance abusers.

The concept of PTSD seems especially relevant for the present study. Many of the women reported significant trauma histories, and many also experienced reactions that might have been diagnosed as PTSD if these women had sought or received psychological treatment. The relationship between PTSD and sexual risk-taking is also relevant, since PTSD may have contributed to the circumstances that led to HIV infection for many of these women.

### **Social Vulnerability**

A complex set of circumstances serves to increase a woman’s social vulnerability to HIV infection. Cultural beliefs and practices concerning sexuality and the role of

women can contribute to vulnerability, as can a variety of economic and social factors.

One of the key cultural issues related to the HIV epidemic concerns the traditions and practices surrounding gender. Gender refers to the socially constructed relationship between women and men. Gender determinants are deeply entrenched in the social norms that assign to women and men a distinct set of productive and reproductive positions and tasks. It is crucial to understand this cultural construction of sexuality, and the socio-economic context in order to understand the patterns of HIV/AIDS transmission, (Kippax et al. 1994; Lear 1995; Orobato and Guyer 1994; Santow 1995; Taylor 1995). Gender plays a decisive role in the area of sexual and reproductive health; ideas of male dominance result in power imbalances that influence sexual risk conduct and create difficulties in changing risk-related behaviour (Catania et al. 1992; Haram 1995; Obbo 1995; Lear 1995; Pleck et al. 1993; Silberschmidt 1991; Talle 1994; Wood and Jewkes 1997).

One implication of traditional gender roles is the low economic and social status of women. A woman's low status because of lack of education, information, and services in health, income, and social rights makes her socially vulnerable to HIV infection (Petros-Barvazain and Marson 1990). The lack of economic opportunities, embedded in socio-cultural practices that are reinforced by the legal system, contributes to women's dependency on their partners. This dependency, in turn, impacts women's ability to protect themselves. Women who are dependent remain in relationships that expose them to risk.

Research has shown that the economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceive to be risky (Heise and Elias 1995; Mane, Rao Gupta, and Weiss 1994; Weiss and Rao Gupta 1998). Thus, the low status of women has great relevance for their ability to protect themselves from HIV infection, as well as influencing the degree of impact that infection with HIV has on the women. Women living with

HIV/AIDS face “double jeopardy” as a result of gender and health-related discrimination. At times, asymptomatic husbands are encouraged to leave their symptomatic wives and find other ones; children too are forced out of the home (Danziger 1994). Moreover, women are often held responsible for spreading both sexually transmitted diseases and HIV/AIDS (Schoepf 1991; Laver 1993).

The impact of poverty further heightens this vulnerability. Women are disproportionately represented among the world’s poor, and the poor are the most threatened by the HIV/AIDS epidemic. Impoverished women may be forced to engage in activities, such as prostitution, that heighten their risk of HIV infection. Further, once they have become infected, the poor are less likely to receive adequate treatment that might retard the spread of the virus and more likely to suffer further economic consequences brought about by their inability to work or to maintain a home. Not only does HIV/AIDS create poverty where it did not exist before, but when it affects those who are already poor, its impact is more intense, because it deepens and prolongs poverty. It affects the networks in which certain societies are woven by breaking up the family and introducing a combined impact of stigma and economic burden (Expert Group Meeting 2000).

### **Structural Vulnerability**

Structural vulnerability has to do with the role of powerlessness in promoting the spread of HIV/AIDS and deepening its consequences. Individuals who are rendered powerlessness due to marginalisation and stigmatisation are put at elevated risk of infection because they cannot make choices that would protect them. Once infected, they are the most devastated by the epidemic, because they have so few resources to begin with. Many women around the world are structurally vulnerable to HIV/AIDS because of various forms of oppression that they face.

Modern feminists have identified with concepts found in the work of Karl Marx, who identified structures of oppression that perpetuated inequalities between management and labour (Niz 2002). Feminist writers identified similar structures of oppression that affect the quality of life for women all over the world (Gamble, Marsh and Tant

1999). These oppressive and deadening (Deen 1998) structures include the exploitation of women on account of their gender, their caste, their class, their lifestyle and livelihood that includes sex work and/or drug use; as well as the physical, emotional, and societal violence experienced by them.

According to Bannerji (1995), the structures of oppression under which women live are a function of power; that is, who has power and how they intend to keep it. At the present time, men maintain control over women through the judicious use of authority and control. Women in many parts of the world live under the authority of men and are controlled by the manner in which men use power. Part of the manner in which men maintain their authority and control over women is associated with the fact that women literally have no name of their own. Instead, women carry the name of their father, until they marry and take on the name of their husbands. The implication here, of course, is that women have no personal identity; and therefore will be unable to create an identity of their own, and certainly will be unable to generate the power that comes with identity.

Farmer (1996) proposes the concept of structures of violence. He suggests that structural violence is visited on all those whose social status refuses them access to the fruits of scientific and social advances because of extreme inequality. Therefore, individuals are rendered vulnerable neither because of individual will nor nature, but because the elements of historical and economical processes of structural violence. Sinha (1999) points out that the poverty and powerlessness in the lives of sex workers in Bombay reveals the structural violence (Farmer 1996) they experience in their lives, that makes them vulnerable to HIV/AIDS infection.

The devastation caused by HIV/AIDS is unique because it deprives families of their young and most productive members. The epidemic reverses human development achievements, deepens poverty, worsens gender inequalities and puts a brake on economic growth. These worsening conditions in turn increase the vulnerability of individuals to HIV/AIDS (UNAIDS 2002a). Moreover, domestic abuse and violence reduces women's control over their exposure to HIV/AIDS. UNAIDS (2000) shows how subservience in marriage, often reinforced by violence, makes women

vulnerable to HIV/AIDS. Additionally UNAIDS (2000) points out that vulnerability to HIV/AIDS is often created by a lack of respect for the rights of women and children. These include rights such as the right to information and education, freedom of expression and association, liberty and security, freedom from inhuman or degrading treatment, and privacy and confidentiality. When these rights are compromised, persons at risk of HIV/AIDS may be stopped or discouraged from getting the necessary information, goods, and services for self-protection. Where individuals with HIV/AIDS risk rejection and discrimination, those who suspect they have HIV/AIDS may evade getting tested and taking precautionary methods with their partners, for fear of revealing their infection; they might even avoid looking for health care.

Mann et al. (1992) observe that in each society, those people who were marginalized before HIV/AIDS arrived, living at the margins of society, are the ones who are most affected by HIV. Women are invariably marginalised by poverty, domestic violence, sex work, and substance abuse (UNAIDS 1999). Women who are made to live on the margins of society exist in both Bombay and Edinburgh. The literature suggests that globally women who are marginalised by their gender are disproportionately affected, and they share an increased vulnerability to HIV (Aggleton 1996; de Zaluondo, Msamanga and Chen 1997; Lindenbaum 1992).

HIV/AIDS also further marginalises persons who were already socially misfits on account of their behaviour: persons such as drug users and sex workers. It also disproportionately affects persons as a result of their ethnicity or wealth, as seen in the HIV/AIDS epidemic throughout the world (Amaro 1993; Catalan et al. 1997; Herek and Green 1995; Paicheler 1992; Thomas 1994). In many parts of the world, HIV/AIDS is seen as a woman's disease, as the women are perceived to be promiscuous (UNAIDS /WHO 2002).

According to the National Commission for Women (1995-96), India, women in sex work suffer the most discrimination in access to health services. Mane (1996) argues that sex workers are viewed as vectors of transmission in India, which heightens their



marginalisation. In Britain, sex workers remain unacceptable as people or citizens (Scambler and Graham-Smith 1992). The issue of violence against sex workers is an area that remains largely under-researched, despite the fact that the scant research, which does exist on this issue suggests that they experience a range of violence from clients, from robbery and serious assaults to rape and murder (Barnard et. al 2001).

Structural vulnerability is a key factor in HIV/AIDS transmission, because all the factors that predispose individuals to HIV/AIDS are aggravated by poverty, gender inequality, the caste system, drug use and sex work, that create an 'environment of risk' (Farmer 1996). Structural vulnerability accelerates and fuels the HIV/AIDS epidemic. UNDP (2002) suggests that countries that rank high on the Human Development Index (that is a composite index constructed from four variables: life expectancy at birth, adult literacy rate, mean years of schooling, and an adjusted measure of per capita economic production) tend to have low HIV/AIDS prevalence (Decosas 1996). The socio-economic gap between the women in Bombay and Edinburgh are realistically portrayed in the Human Development Indicators for the year 2002, which ranks India 124 and the United Kingdom 13. Gilbert (1994) argues that HIV/AIDS is a social epidemic and that it cannot be stemmed without the conscious mobilisation against the cruel structures of oppression.

### The Diagnosis Issue: Impact of an HIV/AIDS Diagnosis

The second chronological stage included in my study covers the period surrounding diagnosis. This stage begins with the decision to get tested for HIV and ends as the woman moves into long-term adjustment to her status. The boundaries of this stage are somewhat fluid, particularly the boundary between the diagnosis stage and the post-diagnosis stage. The idea here is to capture the immediate reactions surrounding the time when the respondent first learns that she is infected with HIV. The key issue for this stage concerns the woman's reactions to diagnosis. What is the impact of this news, and how do the women begin to understand and cope with the new reality of HIV/AIDS in their lives?

This section draws on literature from a variety of sources. The first section includes some of the theoretical and empirical literature on coping with grief, pain, death, dying, and loss. Many of the coping responses that are experienced in other life threatening illnesses are also experienced among people coping and living with HIV/AIDS, and thus this material is relevant here. But HIV/AIDS also has unique meaning and significance, and literature specialized to HIV/AIDS is also covered. Finally, the social impact of HIV/AIDS diagnosis is discussed.

### **Grief, Pain, and Loss**

Grief is a deep and poignant distress caused by bereavement or other major losses. The word has its origins in the Latin 'gravis' meaning heavy or grave (Webster 1998). The expression of emotion during grieving follows a pattern of culturally based beliefs and values (Costello 1995). Therefore, grieving is subjective and is tinted by an individual's societal, cultural, religious, philosophical, and ethnic background. There is a plethora of information on grief. However, for the purpose of this study I am concentrating on the theoretical constructs of Kubler-Ross, (1969) who identified the Five Stages of Grief. Her pioneering work on "Death and Dying" (1969) describes the phases of grief that dying persons or persons with terminal illness experience and the tasks or phases they face before working through their grief. Her stages have been used to describe grief occurring after a variety of losses, including death of a loved one, loss of a limb or a bodily faculty, the 'coming out' or disclosure of a gay child's sexuality, and the experience of intense disappointment.

Kubler-Ross (1969) describes the first stage as Denial and Isolation, which is characterized by an initial feeling of numbness, followed by denial, which acts as a buffer or a temporary defence against the reality of the situation, a feeling of, "this cannot be happening to me" (p. 34-43). The second stage is Anger, which is characterized by feelings of rage, of wanting to strike out at those who are not experiencing the same loss, or anger at oneself for having contributed to the loss. The third stage is that of Bargaining, which is characterized by feelings of unrealistic guilt. It is an attempt to "fix things up, or to bargain with God "to take it all away"(p. 72-74). The fourth stage is Depression, which is characterized by helplessness,

floundering, feeling low, feeling lifeless, and, in extreme cases, feeling suicidal, because the reality of the loss is too heavy to be accepted (p.75-98). The fifth stage is Acceptance which is characterized by a feeling of peace, hope and a new beginning, when the reality of the loss is dealt with and accepted (p.121). Kubler-Ross (1975) identifies a further, sixth stage of grief, which she calls 'Reaching Out.' Reaching out is the essential response to a call to go beyond one's grief to caring for others.

This model is widely quoted and much critiqued. It is important to understand that the order of the stages is not fixed or rigid. Individuals may experience them in any order, and they may seem to experience only a few of the stages. The process is gradual and may consist of a moving forward or backward.

Sherr (1995a) notes that the literature on grieving is peppered with theories about stages and strategies of coping with death and dying. She advises that while these provide useful insights, they need to be utilized with caution, as they cannot incorporate the nuances of the individual experience of HIV/AIDS. The major fear of the unknown, the when and what of death constitute the major concerns (Glaser and Strauss 1968). According to Kubler-Ross (1987) AIDS is the ultimate challenge for humanity. She says persons with HIV/AIDS do generally experience all the stages of isolation, anger, bargaining, depression, and acceptance. In addition they face socio-political, religious, and medical issues. She elaborates how persons with HIV/AIDS experience the various stages. She suggests that when people receive a HIV/AIDS diagnosis, their first reaction is generally denial. Denial according to her is a difficult defence and is not usually maintained for long. She suggests that denial enables a person to continue with life, and in some cases even has a therapeutic effect.

Once persons can no longer maintain denial, anger and rage set in. Anger and frustration weigh heavily on a person's energy and bargaining becomes evident. Bargaining is seen in older children and adults, as well as in family and friends. Over a period of time when it does not yield the desired results, a mixture of anger, frustration, exhaustion, and depression sets in. Kubler-Ross (1987) argues that owing to the stigma of HIV/AIDS, this stage is different from that of patients with cancer or



other more "acceptable" illnesses. She cites in particular the depression evidenced among the gay population. Finally, she asserts that persons with HIV/AIDS will reach the stage of acceptance and peace, like 'all' other terminally ill patients. However she adds that this is only possible if they are given a chance to express their pain and anguish against natural and societal forces.

Acceptance brings with it a positive feeling of peace and calm (Glaser and Strauss 1965; Kubler-Ross 1969). Monbourquette (1992) has added three steps to Kubler-Ross's (1969) stages: 'pardon', allowing the liberation of anger and grief; 'letting-go', a type of goodbye, and 'psychic inheritance' that is permitting the recuperation of memories of the loved one. Griffin (1992) believes that the process of grief as described by Kubler-Ross should include feelings of fear, sadness, anger, shame, guilt, helplessness, uncertainty, love, and acceptance. He suggests that change and unpredictability initiate the process of grief. According to him, persons with HIV/AIDS repeatedly go through the process of grief, from a denial to an acceptance of their illness. Acceptance is not viewed as the last phase, but a new beginning. Bereavement in the context of AIDS presents unique features (Hedge 1996). People are bereaved with AIDS and through AIDS. Thus they experience multiple grief processes: grief for themselves and their loved ones—both alive and dead (Griffin 1992; Barter et al. 1993; Hedge 1996).

People with HIV/AIDS, like other people living with other terminal illnesses, differ in their ability to cope with the probability of their own death. Richardson (1995) believes that the denial process eventually progresses to confrontation. They grieve for their own lost life and others whom they have lost to HIV/AIDS. Kastenbaum (1977) coined the term "bereavement overload" in relation to elderly people who experience the deaths of many friends within a relatively short time. A similar phenomenon was seen with young persons with HIV/AIDS, especially in the homosexual community, where they experienced several deaths within a short span of time (Lehman and Russell 1985).

The course of HIV infection is marked by a series of losses. The diagnosis of HIV/AIDS may result in a sudden and dramatic grief and pain over a variety of losses (Sherr 1995a). Losses associated with HIV/AIDS pervade every facet of a person's life: youth, energy, physical appearance, touching, and contact (Teguis and Ahmed 1992). In extreme cases confusion and dementia set in as well. Social losses encompass loss of privacy, life style, relationships, and peer group in addition to experiences of ostracism and stigmatisation. Psychological losses include self-esteem, innocence, sense of stability, future hopes and dreams, self-image, independence, life, decision-making, certainty, and sex. Finally the financial losses include loss of job, health care and security. Loss constitutes a crucial element of the life experiences of persons with HIV/AIDS, and thus may have a tremendous effect on the changes they undergo and the transitions they make.

HIV/AIDS brings mental, social, and spiritual pain and suffering to an individual. While physical pain is difficult to control, it can be temporarily alleviated through artificial means. However, there is no artificial alleviation of mental, social, and spiritual pain. Saunders et al. (1995) suggest that persons with HIV/AIDS have to face the pain and anguish to emerge from this time of crisis. They reiterate that facing the deepest issues in anguish help the person to come to terms with his pain and develop strengths that help in living with HIV/AIDS and facing the future. They also suggest that surprising growth can be achieved within a short time, as in other situations of crises.

Sherr (1995a) suggests, "the burden of grief is the silent backdrop that looms behind the high profile HIV/AIDS epidemic"(p.ix, preface). Some of the complex psychological issues experienced by persons with HIV/AIDS include grief, bereavement, and the process of death and dying. The experience of grief is widespread and profound in persons with HIV/AIDS, their families, and their communities.

## **Coping With HIV/AIDS Diagnosis**

The diagnosis of AIDS brings with it psychological disturbances and upheavals. The extent and range of emotions experienced is unique and dependent on the person's life experience and the psychological condition before the appearance of the syndrome. Berer (1993) notes that personal testimonies by women describe how profoundly HIV/AIDS affects them. Emotions range from denial to relief about finally knowing the cause of the illness, to an extreme anxiety, to terror and catastrophic shock reaction, to a loss of self-esteem, and to guilt and shame (Lehman and Russell 1985; Miller 1987; Sims and Moss 1995; Hedge 1996).

An HIV/AIDS diagnosis, with its multiple ramifications, generally results in severe stress (Mulleady 1992; Hedge 1996). When an HIV/AIDS diagnosis is confirmed, persons may experience feelings of shock, numbness, disbelief, and anger, (Richardson 1996) followed by intense fear (Miller 1987; Green 1988; Barlow 1992; Berer 1993; Hedge 1996). Persons with HIV/AIDS frequently suffer from periods of depression. The most common reaction to a positive HIV result is reactive depression that is normal reaction to a painful life situation (Mulleady 1992). However, severe depression is not 'natural' in HIV/AIDS patients, who are generally 'ordinary' people without any history of psychiatric problems (King 1989; Firm 1996; Green 1996). People continue to find order and adjust to their diagnosis over the next few months or years. He suggests that most sero-positive people lead fairly functional lives. Nonetheless they have periods of deep distress caused by events which are related to their HIV illness, for example a split up with their partner, discrimination at work, or the death of a friend from AIDS.

Further, research in the fields of HIV/AIDS recognizes that the immune system is affected by stress, because the immune system is directly connected to the psyche by a complex network of nerves, hormones, and neuropeptides, which have a direct impact on an individual's health (Maier et al. 1994). Leiphart (1998) found that survival stress and unresolved grief were among the several factors that adversely impacted on a person's immune function and health.

Taylor's (1983) Cognitive Adaptation Model, which was developed from a study with women living with breast cancer, is a useful model in the understanding how women cope with HIV/AIDS. Coping mechanisms, such as having high self-esteem, deriving meaning from illness, and maintaining a sense of power over one's fate or karma offer a means of coping and ways to live with HIV/AIDS. People living with HIV/AIDS may use a full range of coping strategies. These include emotion-focused coping strategies that improve how a person feels without addressing the problem and problem-focused coping strategies that target the source of stress.

Denial as a means for coping could be beneficial for limited periods. On the other hand, denial that continues for extended periods may delay medical treatment, which in turn may have a negative effect on the person. The use of alcohol and drugs may be seen as a means for coping, especially for persons who have a history of abusing substances. Substance use can also be a means of escape and avoidance. The use of alcohol and drugs to cope with HIV infection is likely to be prominent among people who already have a history of substance abuse (Folkman et al 1992; Chesney and Folkman 1994).

Uncertainty about life, illness, and death is probably the most difficult emotional aspects of HIV/AIDS to manage (Miller 1987; Pierret 1992; Berer 1993; Firm 1996). Persons with HIV/AIDS frequently speak about suicide (Mulleady 1992). Often they have obsessive, repetitive thoughts about illness and death (Barlow 1992). Pugh (1995) suggests that life-threatening illnesses are associated with a suicide risk. Advanced HIV disease was found to increase psychiatric morbidity (Catalan et al 1992; Catalan and Pugh 1995). Further, Barter et al. (1993) point out that suicide is increased up to twofold in patients with potentially fatal diseases. They argue that persons with HIV/AIDS in fact have a higher risk of suicide, and in addition, the possible level of psychiatric morbidity puts them at a further risk of being a group liable to commit suicide. They argue that it is extremely difficult to know the exact rates of suicides in persons with HIV/AIDS, because this population has a high natural morbidity. A person who may have actually died of a drug overdose might be presumed to have died of severe infection. However, both Barter et al. (1993) and

Berer (1993) reiterate that actual suicide is a rare phenomenon. Conversely, McKeganey and Burnard (1992a) cite Skidmore et al's (1990) study in Edinburgh, where they found that suicide was not such a rare phenomenon: a number of drug injectors did in fact die of a drug overdose. The authors conclude that, given the stress that HIV positive men and women undergo, it is not difficult to see how suicide might be seen as a means of dealing with their lives.

### **The Social Impact of HIV/AIDS Diagnosis**

HIV/AIDS has profound implications for social and family relationships (Miller et al. 1994; Bor and Elford 1994). Families experience crisis, disruption, and severe stress (Lloyd 1988; Levine 1994; McGrath et al. 1993). The impact of HIV/AIDS on women and children is devastating, because it affects women not only as individuals who are HIV infected, but also in their multiple roles in the family and community as mothers, wives, caregivers, educators, and providers.

The problems of HIV/AIDS infected women differ depending on the stage of life and HIV infection, socio-eco-cultural and religious beliefs, prior experience of prejudice, and the role each woman plays in the family. Women known to have HIV/AIDS are more likely to be rejected by their families and denied treatment, care, and basic human rights. Albeit this treatment, they tend to bear the main burden of caring for sick family members, including men living with HIV/AIDS (UNIFEM 2000).

There are few diseases in this century that have been met with the degree of fear, prejudice, bias, and loathing against those who develop it (Aggleton and Homans 1988; Lupton 1994). Much of the literature in relation to the social impact of HIV/AIDS reflects the stigma (Namir 1986; Richardson 1987; Miller and Goldman 1993; Schoub 1994) inequalities, and discrimination experienced by people with HIV/AIDS (Lindenbaum 1992) and the isolation they experience (Sutton 1996). HIV/AIDS is perceived as a stigmatised disease, and therefore holds major negative social meanings as a 'disease of difference' (Alcorn 1988; Ariss 1992). Drug use, poverty, and poor housing all form a vicious circle, which perpetuates the cycle of difference, discrimination, and isolation. An HIV positive person may be shunned



because of fear of infection and or a distaste and hatred for his or her lifestyle, either actual or attributed (Gaitley et al. 1993). Gaitley et al. go on to suggest that for the 'moral majority' HIV infection is a symbol of shame and guilt. The 'guilty' include homosexuals, bisexuals, and drug users. The HIV/AIDS epidemic uncovers deeply rooted stereotypes and fears, which result in social discrimination (Paicheler 1992) that creates what Mann (1988) calls the third epidemic.

Thomas (1995) elaborates on Mann's concept of the third epidemic. He points out that there are three phases in the HIV/AIDS epidemic that consecutively attack a society. The first epidemic is the one of silent infection by HIV, which often goes completely unnoticed. The second, after a delay of several years is the AIDS epidemic itself. The third is the epidemic of social, cultural, economic, and political reactions to AIDS. The effects of the third epidemic are discrimination, ostracism, and attacks on civil rights (Connor 1989; Paicheler 1992). Stigma and discrimination are a poignant and painful part of the lived experiences of women with HIV/AIDS.

Many women are tested and start treatment for HIV/AIDS only when their illness reaches an acute stage, and little can be done to improve the quality of their life. This was the case with my respondents in Bombay. Women often fear that the diagnosis will reveal family secrets leading to conflict, rejection, and isolation. HIV/AIDS changes family boundaries if some members are told about the diagnosis and others are not. Depending on the nature of her illness, the women may become physically and psychologically more dependent on her family. Some women may hide the illness for fear of stigma for themselves and their families. They may also hide it from their sexual partner and older children. Sometimes the crisis of illness may serve to reunite the family (Miller and Goldman 1993).

A HIV/AIDS diagnosis has special emotional significance for women in the area of reproduction, sexuality, and childcare. Sherr (1993) enumerates the problems families face in parenting when HIV enters their lives. These include uncertainty of the future, distress at delayed onset of developmental milestones, separation and trauma caused by death and hospitalisation, multiple bereavements, death and dying,



guilt over vertical transmission, multiple infections in the family, economic and social strain, and orphaning of children. HIV/AIDS poses many difficult issues of guilt, anger, recrimination, dependency, and loss (Gaitley et al 1993). While the family remains the most fundamental source of support to women with HIV/AIDS, it may also be a source of pressure and stress to them, because of the special tensions that HIV/AIDS creates (Miller and Goldman 1993). Further, Lehman and Russell (1985) conjecture that women with HIV/AIDS have a double sexual concern. Besides transmitting their disease to their partner, they may also risk contracting a sexually transmitted infection, which would further compromise their health. Fear, lack of energy, and moral considerations of spreading the illness all result in a loss of sexual activity.

## **The Post-Diagnosis Issue: Long-Term Adjustment**

The final stage covered by my study is the post-diagnosis stage. This stage begins after the woman has adjusted to the initial impact of diagnosis and continues indefinitely. The key issue here is long-term adjustment. How do women make sense of their lives and find new ways to live with HIV/AIDS? This section introduces the concepts of turning points, transitions, and transformations as a framework for understanding change. These concepts are then applied to understanding long-term adjustment to HIV/AIDS.

### **Turning Points, Transitions and Transformations**

Several researchers have explored and defined the three concepts of turning points, transitions and transformations. These three concepts are interdependent, but when examined together, they help to develop a fuller perspective of the aspects of change in the lives of positive women. All three concepts imply some notion of change, but there seem to be subtle distinctions among these. The following sections discuss the similarities and differences among these constructs and point out the relevance of each for my study.

**Turning Points.** Wheaton and Gotlib (1997) argue that turning points have an intuitive meaning, although there is distinct lack of precision in their identification and definition. They see the life course as a path or a road on which all individuals travel. A turning point, they propose, deflects an individual off the path because it is a disruption in the individual's trajectory, or continuation of the direction being taken. They describe turning points as crucially important moments in a life history that change the direction of the life course, such that they could alter the probability of life destinations.

Denzin's (1989a) description of "epiphanies" runs in a similar vein. According to him epiphanies are those "interactional moments" (p.70) that leave a mark on the lives of people and have the potential of creating transformational experiences for them. He argues that after a person experiences an epiphany; his or her life can never be the same. Therefore he points out that any event, transition, or change that alters the life course permanently is a turning point. He points out that his (1989) "existential interpretive" perspective, which describes epiphanies, is a useful approach when applied to the study of personal troubles and turning point moments in the lives of interacting individuals, because it focuses on those life experiences that radically shape and alter the meanings persons give themselves. He notes that they are interpreted as "turning points" by the respondent and by others. Moreover, he suggests that by studying these, the researcher is able to highlight the moments of crisis.

Denzin (1989b) classifies "epiphanies" as major, cumulative, illuminative (or minor), and relived epiphanies. The major epiphanies touch every fibre of a person's life; their effects are immediate and long term. The cumulative epiphanies represent eruptions to events in the past, the minor ones symbolically represent major problematic moments, and the relived ones are the ones in which the effects are felt immediately, but the meaning is only felt in retrospect. A major event may, at first be major, then minor, and then relived. A cumulative epiphany will erupt into a major event in the life of an individual.

Denzin's (1989b) study of epiphanies provides a fitting theoretical foundation for understanding the lives of positive women, who may experience epiphanies or life altering events as a result of being diagnosed with HIV/AIDS. Moreover, being diagnosed, as HIV/AIDS positive could be a major 'epiphany' as it touches nearly every fibre of an individual's life, a 'turning point' after which the individual's life is never the same.

**Transitions.** Transition is defined as "movement or passage from one position, state, stage, subject, concept etc. to another" (Random House Dictionary 1967). Williams (1999) suggests that the transition process appears to be a fundamental human survival mechanism. He believes that it is the mind's way of making sense of major life events and adapting to change. Golan (1981) refers to the work of an early social scientist James Tyhurst (1957) who studied this phenomenon. He points out that the term is derived from two Latin words that mean, "to go across". He defines transition as "a passage or change from place or state or act or set of circumstances to another" (pp 149-169). Vaughan (1986) states that the transition process is marked by the coincidence of departure and arrival, a going from and coming to. Brammer (1991) suggests that life transition refers to a journey through, often to something unknown. The element of journey, travel, movement from one place or state to another is the common thread that runs through all these definitions.

Hopson and Adams (1976) have developed a seven-stage model of the transition process. They suggest that the phases represent a cycle of experiences, which involve disruption in the beginning of the transition (immobilization, minimization, depression). This is followed by a gradual acceptance and letting go after some time has elapsed, during which the individual tests out new forms and ideas, understands oneself, and incorporates changes in one's behaviour. The final phase is characterized by a search for meaning and internalisation of the new transition. Their model is similar to Kubler-Ross's (1969) stages of coping with death and dying. The beginning stages of transition coincide with Kubler-Ross's stages of denial and isolation, bargaining, anger, and depression. The later stages in Hopson and Adams's

(1976) seven-stage model of the transition process all come into the purview of Kubler-Ross's stage of acceptance.

So while turning point refers to the event that changes lives, transition refers to the journey or the path taken because of that change. Transition seems to be the beginning or unfolding of a process. Linked to the aspect of travel and journeying is the aspect of a new direction and redefining of roles. In the case of HIV/AIDS diagnosis, the process of transition is multifaceted, because of the many complex and difficult adjustments that people must make once they have a positive diagnosis. These can include practical adjustments in lifestyle, health care, sexuality, living arrangements, and means of livelihood, as well as more psychological adjustments related to self-image and aspirations for the future.

**Transformations.** Wheaton and Gotlib (1997) suggest that when the individual makes a transition, his or her role in life gets transformed, redefined, or left behind for a new role. Non-normative transitions are crisis events that may offer potential for development (Mercer et al. 1989) and sometimes lead to transformations. The change strategies utilised by individuals can either impede or enhance the natural psychological process of transition that enables individuals to adapt to change and transform their lives (Adams et al. 1976). Tatelbaum (1981) suggests that when a person experiences grief, pain, and suffering he or she is confronted with a profound challenge, which leads to transformation. She points out that this change is apparent in behaviour, values, attitudes, way of living and viewing the world that helps people to grow into individuals who aim to reach previously untouched domains, live life more fully, learn to live now, appreciate life anew, move beyond their sorrow and pain, engage in life affirming actions, create, reach out to others, and enhance their own lives and the lives of others. However, all transformation and change are not positive, just as, all movement is not forward. A positive diagnosis is a profound challenge that seemed to describe transformation in the lives of my respondents.

## **HIV/AIDS Diagnosis as Turning Point, Life Transition and Transformation**

My review of the literature has found few studies that look at the HIV/AIDS diagnosis as a turning point, a transition, or a transformative experience. The limited material that was found will be discussed here.

O' Sullivan and Thompson (1992) in their book "Positively Women Living with AIDS" found that a positive diagnosis generally affected women in a profound way, and that it acted as a turning point in their lives. For many women it marked the end of a chaotic lifestyle of drugs and sex work, and the beginning of a dynamic response to living with HIV/AIDS in the face of many adversities. This finding seems to correspond to the notion of transformation as described in the theoretical literature.

In a study on the centrality of meaning making in transformational learning and how HIV-positive adults make sense of their lives, Courtney et al (1998) also found that an HIV/AIDS diagnosis was followed by a post-diagnosis turning point, called a "catalytic experience" (p. 71). All participants had a clear post-diagnosis turning point that involved social interaction. It is unclear whether these participants could be described as undergoing transition and transformation as described in the theoretical literature.

The Population Council (2001) conducted a study in the area of HIV/AIDS and transitions. Transitions in this context referred to the normative life cycle transitions of childhood, adolescence, adulthood, and middle age to old age. They studied the transitions to adulthood among young people in the context of AIDS in South Africa. Their goal was to contribute to the design and refinement of policies and programs to help young persons make healthy life transitions from adolescence to adulthood. They found that "connectedness", along with a stable, supportive, and consistent family and community relationships were the key issues in making healthy transitions.

Although these studies suggest that the concepts of turning point, transition, and transformation may be relevant in the understanding of HIV/AIDS, they do not

directly address the issues I envision in this study. I have found no studies in the area of HIV/AIDS and transformations, in the way that I have used transformations as a personal change or movement, although there are studies that examine transformation in its social context. It is hoped that my study will make a significant contribution in this area, by using these concepts to understand the complex change process involved in long-term adjustment to HIV/AIDS.

## Conclusion

This literature review has examined the theoretical and empirical context for my study. I have used the three chronological time periods covered in my study as a framework for organizing the literature, focusing on a particular issue that is germane for each of the three stages. These issues will be revisited as the findings for each stage are discussed. The next chapter describes the methods utilised in the study and relates my experiences during data collection. This provides an understanding of the methodology utilised and a window to conducting an in-depth inquiry into the lives and experiences of positive respondents.



## CHAPTER 3: METHODOLOGY

### Introduction

The previous chapter reviewed the body of literature in the fields of HIV/AIDS and the theoretical constructs that informed my study. This chapter describes the research methodology utilized in the study.

The central purpose of my research was to understand the women's experience of living with HIV/AIDS from their own perspective and to examine the turning points, transitions, and transformations they faced along the course of their lives, from the time before they were diagnosed up to the time they were interviewed. To that end I wished to focus on their subjective understanding of being positive, the ways that HIV changed their views of themselves, and the processes of personal change and development engendered by living with HIV/AIDS.

The first section presents the philosophical background of my study. The next section describes the various aspects of the research design utilised in my study, along with the rationale for carrying out the research the way I did. The next section discusses the varied ethical issues that arose while researching the sensitive subject of living with HIV/AIDS, with women who belonged to a vulnerable section of the population in Bombay and Edinburgh. The section that follows discusses the impact that telling their stories had on the respondent. The final section is the Conclusion.

### Philosophical Perspectives

Philosophy can be defined as "the critical examination of the grounds for fundamental beliefs and an analysis of the basic concepts employed in the expression of such beliefs" (Encyclopaedia Britannica 1998). A philosophical perspective was crucial for this study because research is directly linked to the assumptions commonly accepted concerning ontology, epistemology, and human nature (Morgan

and Smircich 1980). Since I utilised a qualitative paradigm in this research, I found that an articulated philosophical perspective was essential in developing the clarity and rigour necessary to interpret the social world of the respondents in this research.

A constructivist paradigm (Denzin and Lincoln 1994) was chosen as the philosophical perspective for this study, because the focus of the research was on attributes of life experiences and lived realities. Adopting a constructivist epistemology of knowledge allowed for accepting that the respondents were the “experts” and knowledgeable about their own lives, because they were the ones who were living with HIV/AIDS. Further, a constructivist paradigm, which contained varying aspects of the phenomenological and feminist perspective toward research, was found to be appropriate because it provided a lens through which the study could be developed and a foundation for data collection and analysis.

### **Phenomenological Perspective**

Phenomenology is more than a research method; it is a philosophy that emerged from a growing discontent with a philosophy of science based exclusively on the study of material entities, which ignored the cultural and social context within which the entities exist. Hegel (1807) held that phenomenology referred to knowledge as it appeared in the consciousness of an individual, from what he or she perceived, sensed, and knew in his or her immediate experience. Therefore, the aim of phenomenology is to determine what an experience means for the individual who is living it, because having lived through an experience, the individual can provide a comprehensive description of it (Moustakas 1994). A phenomenological perspective refers to the respondent’s perception and construction of meaning, as opposed to the phenomenon that exists external to that respondent (Husserl 1913/1962, Leedy 1997).

This research sought to develop an understanding of the meaning of the phenomenon of living with HIV/AIDS. By utilizing aspects of the phenomenological perspective, it was possible to gain insight into the phenomenon from the perspective and voices of the positive women themselves, because the reality of living with HIV/AIDS was

an inextricable part of their consciousness. This insight led to the discovery of the patterns that were connected to form the essence of women's lived experiences of HIV/AIDS. Thus, utilising aspects of the phenomenological perspective was a powerful tool in facilitating a more comprehensive understanding of the subjective experiences of the respondents.

### **Feminist Approach**

At the centre of this approach is the critical insight that there is no one truth, authority, or objective method that leads to the production of knowledge (Spender 1985). The decision to utilize a feminist approach in this study was inevitable for four main reasons. First, the experiences of positive women were the major focus of the study. Second, one of the major objectives of the study was to attempt to view the world from the perspective of the women themselves. Third, central to the research were the active voices of the positive women, heard through the women's own accounts. Finally, the nature of my study itself contained many elements that can be characterized as a feminist approach (Duffy 1985). For example, I was a woman researching other women, who viewed the personal experiences of the respondents through the lens of gender.

The purpose of the study was to study positive women, with a focus on their life experiences; thus, the study itself was gender specific. The research had the potential to help the respondents by providing a space in which their voices and stories about their lives, often silenced or marginalized, could be heard, as well as the potential to help me as the researcher by providing an opportunity for vicariously experiencing the lives of other women. Farmer and Klienman (1989) argue that HIV/AIDS develops from and adds to the vicious cycle of human suffering. They suggest that a compassionate involvement with positive people necessitates a careful listening to their accounts. As a woman I was well suited to listen carefully to the accounts of positive women, because, as pointed out in academic studies, women's sense of self is more relational than men's, therefore women are more likely to be emotionally attuned and expressive (See Davidman, 2000 for examples). The focus on the

emotional landscape of the women's response to HIV/AIDS thus fits well with the feminist perspective.

The research was also characterised by a trusting, non-hierarchical relationship, where expressions of feelings and concern between the women and the researcher were exchanged.

## Research Design

A research design is the researcher's overall plan for obtaining answers to the research question (Polit and Hunglar 1989). The following sections describe my overall approach as well as the specific procedures I used to carry out this study.

### Qualitative Paradigm

A qualitative approach was considered to be the most appropriate method for studying the phenomenon of women living with HIV/AIDS. This is because questions concerning how people make sense of their lives are best understood through qualitative analysis (Lawless 1993). The definition of qualitative research depends on the philosophical and theoretical perspective of the researcher. For the purposes of this study, qualitative research refers to research that centres on understanding the meanings that women gave to their experiences with HIV/AIDS as they were lived, felt or undergone (Sherman and Webb 1988). Utilizing the qualitative research paradigm facilitated data collection in naturalistic settings that highlighted the complexity and diversity of the research content. It involved asking simple questions and getting complex answers from the *emic* perspective or the perspective of the women themselves (Merriam 1998).

Further the qualitative paradigm offered the best opportunity for understanding what the respondents thought and felt in a holistic person-centred way, such that it was then possible to uncover and examine their lived experiences (Holloway and Wheeler 1996). Moreover, it provided the opportunity to establish rapport and trust between the respondents and the researcher and thereby to elicit deep, meaningful responses.

Finally the qualitative paradigm presented a range of methods from which to choose. Like the *bricoleur* (Levi-Strauss 1966, Denzin and Lincoln 1994) I pieced the most appropriate methods together, forming a *bricolage* of methods that facilitated an understanding and interpretation of the phenomenon under analysis (Denzin and Lincoln 1994).

### **Life History Method**

Life histories are stories that individuals tell about their lives (Josselson and Lieblich 1993). Life histories provide flavour to qualitative studies because of the subject matter they study and the narrative form in which they are written (Marshall and Rossman 1989). Despite its common occurrence in research, the precise definition of the term "life history" remains ambiguous (Reissman 1994) and is used interchangeably with the terms life stories, life accounts, oral histories, and personal narratives. These terms generally refer to a particular kind of text that is organized around consequential events in the narrator's life. The listener is taken into the narrator's past, where the narrator recapitulates what happened then to make a point. In order to create understanding, the narrator uses narratives, or stories that are told about an experience. Respondents generally construct their narratives as dramas in three parts, beginning with a *prehistory* or a *beginning*, the *incident* or the *middle*, and ending with the *aftermath* or an *end* (Cohler 1982; Sherman and Reid 1994).

The life history method was utilized in this study because it is especially useful for studying problematic lived experiences of people that focus on "epiphany" or turning points (Denzin 1989a) and transitions (Josselson and Lieblich 1993). The life history method emphasizes the value of the respondents 'own' account (Marshall and Rossman 1995) in their 'own' words; and enables them to interpret the past and make it acceptable, understandable, and important (Helling 1988; Watson and Watson-Franke 1985). The life history method is also well suited to research involving women with little education, because it enables them to use their own words to relate their innermost observations, feelings, as well as social and personal experiences in a natural way; thus, highlighting the story of the culture and society to which they belong (Bertaux 1981). Utilizing life histories that were created in telling,



listening and understanding, that emphasized the meaning of events, rather than the events themselves (Cohler 1994) helped to address the experiential truth of the respondent's lives.

The dimension of time is intrinsic to the life history approach (Tesch 1990). Life histories may be structured in a chronological sequence covering a long period of time (Holloway and Wheeler 1996), allowing for the study of the major life events of respondents, revealing life's passages, and focusing on the experiences and feelings of the individuals as they passed through the different stages of life (Taylor and Bogdan 1984). For the purposes of this research, the topical life history method (Denzin 1978) was utilized because only one part of the women's lives was studied, rather than studying their whole lives (Minichiello et al. 1990). Women's accounts were constructed according to the three stages that marked the progress of the HIV illness: the pre-diagnosis stage, the diagnosis and the post-diagnosis stage. Interviews lasted an average of two to two and a half hours.

## **Two Cultural Perspectives**

As discussed earlier, HIV/AIDS has spread throughout the world's population, on every continent of the world (Mertens and Low-Beer 1996; UNAIDS 2001). It is a complex, global pandemic that respects no geographical boundaries (Gould 1993). To develop a deeper understanding of women's experiences of living with HIV/AIDS, I chose to study women in two different countries: India and the United Kingdom.

This provided me with two distinct cultural perspectives on the experience of HIV/AIDS, one from a developing nation with a strong traditional culture, and one from a developed nation with a more modern culture.

With the phenomenon of globalisation and growing internationalisation, more people cross national borders, exporting and importing social and cultural manifestations. This has led to the establishment of international organisations that foster a global understanding of problems and intervention into these problems. This is especially



relevant in the case of HIV/AIDS, which is readily capable of crossing national and cultural boundaries. A perspective that extends its understanding of the life experiences of positive women across two cultures provides a broader and deeper insight into the realities of this epidemic. Although this study is too limited in scope to be a truly cross-national study, it does provide insights that may be useful in developing more comprehensive studies across different cultures.

## Procedures

### **Selection of the Sites**

I planned to study positive women in Bombay (India) and Edinburgh (United Kingdom). My choice of these two sites was based on three main considerations. Firstly, both cities had the dubious distinction of being called “AIDS Capitals” and would provide rich and valuable data. Secondly, they offered me the possibility of placing my study in the two different world contexts of developed and developing nations, and lastly, I was familiar with both cities: Bombay being the city I was born and brought up in, and Edinburgh being the city I was studying and living in.

The choice of a research site for a qualitative study is characterised by a balance of research interest and availability (Padgett 1998). Given the sensitive nature of my study, choosing an appropriate site for the study and developing a relationship with its members was a key concern for its implementation. I located organisations in both cities that worked with positive women. Three organisations in Bombay and two organisations in Edinburgh agreed to meet me. I set up meetings with them and explained the subject of my proposed research. All the organisations were receptive and keen to provide information. However, only one organisation from each of the study sites granted me permission: ARCON in Bombay and Solas in Edinburgh. The other organisations that did not grant me access in Bombay cited shortage of staff and inconvenient timing as the reasons. Whereas, in Edinburgh the rationale cited for

not granting permission was based on the issue of the potential respondents being over researched.

After conducting a basic exploration of the probable sites, I discovered that both these organisations had the potential of providing sites whose clientele were representative of the populations they served, which would increase the generalisability of the study. Additionally both the sites were suitable because of practical considerations such as ease of access to the informants and adequate tape-recording facilities. Importantly, neither site had any features that might adversely influence the respondent's accounts, for example, the close proximity to family or employers.

The *raison d'être* of both organisations was the support of persons living with HIV/AIDS. I had a few informal discussions with staff members of both organisations to discuss the overall objectives of my study and the proposed plan of fieldwork. This was followed by a formal, written request seeking permission to conduct my fieldwork.

**ARCON, Bombay.** Bombay (Mumbai) is the capital of the State of Maharashtra, the second most populated city in India. It has been called the "AIDS capital" of India (Bharat et al. 2001) and the "AIDS capital" of the world (Specter 2001). This uncertain distinction and the high number of reported cases may be explained by the fact that it was one of the first cities in India to establish HIV testing facilities, which were established in 1996.

My interviews were conducted at the AIDS Research and Control Centre (ARCON), which is a unique collaborative programme of the Government of Maharashtra and the University of Texas, Houston, set up in 1994. ARCON is a technical, semi-governmental institution. It conducts medical and behavioural research, trains health care workers, develops replicable models for priority interventions, and provides technical expertise to the state of Maharashtra, the Government of India, and to International agencies. ARCON's focus on providing diagnostic and socio-psycho-

medical aspects of treatment to their clients was expressed in the fact that they referred to their clients as “patients”.

**Solas, Edinburgh.** Edinburgh is the capital of Scotland, and has been called the “AIDS capital” of Europe (Des Jarlais and Case 1992). It earned this unappealing sobriquet because of three simultaneous events in the mid-eighties that caused an outbreak of HIV. The events were the increasing popularity and cheap supply of heroin, the methods by which heroin was injected, and the frequency of sharing equipment owing to the difficulty of obtaining sterile needles.

I conducted my interviews at Solas (a Gaelic word meaning light and comfort), an organisation that offers support services, information and an informal meeting place for people living with HIV/AIDS since 1991. It is a part of the Waverley Care Trust whose aim it is to promote the welfare of positive people residing in the Lothians and to support their relatives, carers, and dependants. Additionally the organisation aims to support positive people to make affirmative choices about healthy living by offering a wide range of practical and emotional support services such as counselling, support groups, buddy services, alternative therapies, information services, and a café. Solas’s focus on providing the varied aspects of psychosocial support and information services to both the person living with HIV/AIDS and their families was reflected in the way they referred to their clients as “women.”

### **Selection of Respondents**

Limitations on population size and availability made formal sampling techniques unworkable for this study. Therefore, a convenience sampling technique was utilized, whereby respondents were included in the study on the basis of their availability (Padgett 1998).

An important methodological issue was the number of respondents to be chosen for the study. There is no absolute right answer about the appropriate number of participants in qualitative research. It is suggested that the number needs to be judged within the context and the purpose of the study, and be seen to reflect the resource

availability (Patton 1990). In the initial conceptualisation of the study, fifteen women from each context were considered to be the maximum number of participants.

To add to the richness of the data, I envisioned selecting women who represented the progression of HIV/AIDS: asymptomatic, symptomatic HIV, and what used to be called 'full blown AIDS'. Therefore five women at each stage of the illness from Bombay and Edinburgh were envisaged; however, I found that this method of selecting respondents was unsuitable in both contexts because of the women's uncertainties around HIV and its progression. After conducting a few early interviews in Bombay, I realised that ascertaining the progression of the illness from the women themselves was proving difficult. This was both because I felt uncomfortable about questioning the women about the progress of their illness at the very outset of the interview; and because most of the women did not appear to differentiate between the stages of the illness themselves, using the words HIV and AIDS interchangeably. I needed to reconsider this category, and went on to collect a respondent group based on availability and willingness regardless of the progression of their illness.

After the interview I asked the women to allow me to obtain information about the progression of their illness from their case files. All the women agreed to this. Although I was able to ascertain the HIV status of the women, after discussions with my supervisors, it was decided that I would not use the stage of illness as a criterion against which experiences were explained. Nevertheless this would be an interesting area for future research.

Interestingly, however, the final study group consisted of women at different stages of their illness in both Bombay and Edinburgh. Moreover, the number of respondents in Edinburgh was restricted to twelve instead of fifteen, as envisaged, because of the difficulty in obtaining respondents and the constraints of time. Obtaining "information-rich cases that manifest the phenomenon of interest intensely" (Patton 1990, p.171) compensated for this slight reduction in numbers.

## Data Collection

This section describes the data collection process: the qualitative interview guide, the pilot, the methods of contacting respondents and interviewing procedures, access and consent and finally my experiences in data collection in Bombay and Edinburgh.

**The Research Tool.** Interviewing is one of the most common methods for collecting data in qualitative research. Interviews offer an opportunity for respondents to provide rich, contextual descriptions of their experiences. Interviewing also allows the researcher to enter the respondent's perspective (Patton 1987). I used a semi-structured interview guide that included elements of both structured and unstructured interviewing, also known as in-depth-interviewing (Cohen and Manion 1996). I used structured interviewing by asking explicit questions of all the respondents, and unstructured interviewing by asking open-ended questions and probes. Open-ended questions are flexible and allow the interviewer to probe deeper into issues. They may serve to clear any misunderstandings that might arise in the course of an interview and help the interviewer to make a clearer assessment of what the respondent is actually trying to say (Cohen and Manion 1989). Questions and probes were focused on developing an empathic grasp of the phenomenon of living with HIV/AIDS.

The Interview Guide was developed in five sections, namely, biographical information, the pre-diagnosis stage, the diagnosis stage, the post-diagnosis stage and looking ahead. I asked women to start their accounts from the time before they discovered they were positive. I did this because I wanted to understand the unfolding of events in their accounts and the life experiences at each stage. I utilised elements of the topical life history method (Denzin 1978). The topical life history attempts to cover a particular phase of the respondent's life experiences. Therefore, the questions in the interview guide were designed to flow from the time just before diagnosis until the time when the interview was conducted. The questions were also constructed such that the women could use narratives to explain their life experiences (Denzin and Lincoln 1994). Narratives give face to the HIV epidemic, adding flesh and blood to statistics and rigid categories and concepts (Klitzman 1997).

The act of asking the respondents to “think back” to past experiences helped to transport the women into their past reality (Patton 1990). I utilized Leininger’s (1985) concept of the “idea gate” while developing the interview guide. This involved asking questions that used sentences such as, “Could you tell me” or “I would like to know more about”. She suggests that utilising this method tends to open the ‘idea gate’ and that these questions provide stems that allow the respondents to share their story, in their own way, thus making it unnecessary for the researcher to ask too many questions. To ensure that the questions were easy to understand, I made them short and devoid of jargon (Kvale 1996). Experience questions were asked before the feeling questions, that is, asking “What happened?” before asking “How do you feel about it?” (Patton 1987).

**Pilot.** I conducted two pilot interviews in Edinburgh, one with a service user of Solas and the other with a peer from the Department of Sociology, who role-played the part of a positive woman. I felt it would be unethical to put more than one positive woman through the experience of an interview; hence the pilot interviews were limited. Moreover, given the sensitive and demanding nature of the research, I felt that it was important to restrict the number of pilot studies.

Additionally the potential respondent group available for the research in Solas was relatively small in number, so that conducting pilot studies might create practical difficulties in obtaining an adequate number for the study. For the same reasons, no pilot was conducted in Bombay. Moreover in Bombay I had the practical constraints of limited time for fieldwork.

The purpose of the pilot with the positive respondent was to uncover and modify problems with the interview protocol and to gain a deeper insight into the perspectives of a positive woman. It was also to test the clarity and the flow of questions and to rehearse the process of interviewing. The purpose of the pilot with a peer was to rehearse the interviewing process.



Two changes were made as a result of the pilot. The first involved references I made to HIV/AIDS and God. For example, in the pilot I asked my respondent about her feelings when she received an AIDS diagnosis, and whether having AIDS had affected the way she felt about God. She suggested that the use of the words AIDS was painful to her and that I should substitute the words with “positive” or “the virus.” Her suggestion is reflected throughout the study. I have chosen to refer to the respondents as “positive women,” rather than using one of the more common descriptors, such as “HIV-positive” or “AIDS patient.” Utilising appropriate language is crucial; because it shapes the way in which persons with HIV/AIDS view themselves; and the way in which care professionals and society in general perceive view them (POZ 1996). Additionally, she believed that the word “God” was limited, and that some women may say that they did not believe in God, but rather in some sort of spiritual force or faith. I incorporated these minor suggestions into my Interview Guide.

The second suggestion was more substantive. Throughout the interview I repeatedly asked the respondent to tell me what she was feeling at each point of her account. My respondent drew my attention to the fact that it was emotionally and physically tiring to keep revisiting painful emotions, added to which she said it was mentally exhausting to try and recall specific feelings at specific points, given the period of time that had elapsed between the events. It was interesting that my peer and the Manager at Solas also commented on the excessive questioning about respondent’s feelings. Cautioned by all their comments I was judicious in asking the “feeling” questions. Their perspectives were crucial in streamlining the length of the interviews and helped to bring an even flow to the interview.

**Access, Entry, and Consent.** Prior to data collection, I sought formal permission to begin my fieldwork from both ARCON and Solas. Both organisations granted me permission to do so. I then began the process of building a relationship with “gatekeepers” at both sites that is persons who introduce the researcher to the field in qualitative research (Lincoln and Guba 1985). It was essential for me to build a trusting relationship with the gatekeepers, because they facilitated my relationship

with prospective respondents. At ARCON the counsellors and one doctor were the gatekeepers; in Solas the Manager and the Facilitator of the Women's Group were the gatekeepers. I spent time discussing my study, obtaining their views about the study, developing an insight into the 'culture' of the respondents (Lincoln and Guba 1985). They in turn explained the study and encouraged women to participate in my study.

Having built a trusting relationship with the gatekeepers, I worked on seeking consent from individual respondents to conduct the study. Given the sensitive nature of the subject of my research, confidentiality and informed consent were vital prerequisites. These components of the research process were dealt with carefully and thoroughly.

In Edinburgh before I began the process of data collection, I met quite a few prospective respondents in the Women's Group. I was invited for two sessions, one an Art session and another an informal chat session, in which the Coordinator introduced my study and me to the women. However I met the majority of my respondents at a Women's Day organised by Solas. The gatekeepers introduced me to women whom I had not met before in the Women's group. I had informal conversations: some were interested in knowing more about the study and agreed to participate. I asked women how I could contact them. We exchanged phone numbers and times when I could contact them. These meetings provided me with informal rapport building opportunities and assisted me in the process of "prolonged engagement," that is, the possibility of spending time with the respondents to build trust and learn their culture (Lincoln and Guba 1985), thus enabling me to build my credibility. Two respondents in Edinburgh were introduced to me by one of my respondents; they were not affiliated to any organisation in Edinburgh.

Through a letter I requested women in Bombay (Appendix C (i)) and Edinburgh (Appendix C (ii)) to participate in my study. The letter provided a written explanation of the purpose and aims of the study, the research methods employed, the voluntary nature of the study, the freedom to withdraw from the process at any

point, and an assurance that their privacy and confidentiality would be protected. A mention was made of the fact that the information contained in the transcripts would only be discussed for academic reasons with my academic tutors. However, following a request from the Director of ARCON, I needed to modify the letter to respondents in Bombay to include the fact that the staff at ARCON would also share the anonymous information for therapeutic purposes. It was ethical to highlight why the study was important and how it would possibly benefit the respondent as an individual woman living with HIV/AIDS (NHMRC 2001), as well as benefiting positive women collectively.

To protect the rights of the respondents I prepared a letter of informed consent (Appendix D (i) and (ii)) that briefly stated that the respondent had understood the details of the research study, its aims and purposes, the time required, the methods to be utilised, the recording of the interview, issues of confidentiality and anonymity to be maintained by the researcher, and their right to ask questions, to not answer questions, and to withdraw from the process if they so desired at any point. I explained the concept of informed consent to help them in their decision-making (NHMRC 2001) before requesting them to sign the letter.

To ensure the confidentiality of the process, these letters were generally given to the respondents at the beginning of the interviews. In Edinburgh however, some of the women suggested that they would like to know more about the study prior to the interview. After obtaining their permission and postal addresses, I posted a copy of the letter to their homes. At the time of the interview I read the invitation aloud to each respondent, and encouraged them to ask questions about the study before making a decision to take part and signing the written consent form. Most of the women in Bombay and all the women in Edinburgh were willing to sign the letter of consent.

A few women in Bombay expressed an initial feeling of discomfort about "signing a paper." They said that they did not want to be involved in any legal contract that bound them in any way. I once again explained the concept of the letter of consent

reassured them of the purpose of the letter of consent and how it in fact obliged me to maintain their privacy and confidentiality. Nonetheless two women refused to sign the letter of consent. I asked them whether they were willing to be interviewed and they said that as long as they were not made to sign something, they were happy to do so. Having obtained their oral consent I continued to interview them. I made certain to reassure these women at different stages of the interview, as I did not want this to create any sort of barrier, however subtle, in the narration of their accounts. I accepted the fact that some women found it difficult to have a deep understanding of an academic study and appreciate the implications of consent, which must seem like a totally pedantic concept to them. Both letters were translated into Hindi, Marathi, and Gujarati for respondents in Bombay.

**Presentation of Self in the Field.** Before starting my fieldwork, I engaged in a process of reflexivity with my supervisors. Reflexivity refers to the ability to examine how personal attributes of the researcher, such as age, gender, social class, professional status and race may affect the collection of data and the distance between the respondent and the researcher (Pope and Mays 1996). Reflexivity in qualitative research is crucial since the researcher serves as a kind of instrument in data collection and analysis (McCracken 1988). It was decided that to enhance the credibility of my findings, I would maintain a research diary to record my thoughts in relation to events that were related to the issues mentioned above.

It was also important for me to reflect on my position vis-à-vis my relationship with the respondents along a detachment-attachment continuum (Padgett 1998). That is, what level of participation did I intend to maintain? Qualitative researchers diverge to a great extent in how they present themselves (Schatzman and Strauss 1973). It was felt that involvement should be judged according to the circumstances of each individual interview, keeping in mind the fact that I wanted to create a humane, egalitarian relationship between the respondent and myself.

Further, since my study was set in two different countries, one of which I was a citizen and the other in which I was an alien; I needed to address issues about being

an insider or an outsider. Oakley's (1981) description of the "insider" articulates a central strand of the feminist perspective. She points out that the insider's perspective is developed from the shared experience of being a woman. Dube (1975) distinguishes between the expectations of a woman researcher who is an insider from one who is an alien. She argues that the former is a more difficult status to negotiate.

As a woman in her mid-thirties I shared gender with all my respondents and was very much an insider. As an Indian woman, I shared nationality with my respondents in Bombay that made me an insider for them, but an alien for my respondents in Edinburgh. However, although I was an Indian woman I did not share the cultural background or socio-economic status of my respondents in Bombay. I belonged to a different social world and was therefore an outsider. Paradoxically, because I possessed a systematic knowledge and exposure to people who belonged to my respondent's social world, spoke their native languages fairly fluently, and hailed from the same town as most of them, it led to a development of knowledge, skills and awareness in relation to my respondents making me an insider. Similarly, because I did not share the cultural background or socio-economic status of the majority of my respondents in Edinburgh, I was an outsider for the majority of them, and yet being a native speaker of the English language, made me an insider.

Due to these varied combinations and permutations, I was in an ambiguous position of being an insider and an alien. I believe that my position, somewhere in between, worked well for me. It helped the respondents to respond freely and fearlessly to an insider. As an alien my objectivity was sharpened, because the distance ensured that my own experience was not leading the progression of the interviews.

**Method of Data Collection.** In Bombay I met women who were visiting ARCON as outpatients. They were generally introduced to me by the gatekeepers, who had already briefly oriented them about the study and me. At other times, I introduced myself and the study to women who were sitting in the waiting room. I asked those women who agreed to be interviewed to inform the counsellor about their willingness to participate in the study, when they visited the counsellor either before



or after their visit to the doctor. The counsellor would generally invite me into her room for a few minutes, and re-introduce me to her patient, and briefly reiterate the woman's willingness to participate. I believe this process helped the women to build trust in an outsider. The date, time and place for the interviews were fixed. Interviews were usually conducted on the same day or the next day.

Given the sensitive nature of my study, it was decided to interview women only once, for approximately two to two and one-half hours. I was able to follow this plan for most of the interviews in Bombay, excepting on three occasions, where the women asked to stop because they did not have time to continue. In all three cases, the second interview was held the very next day. This made a total of 18 interviews in Bombay. Except for two interviews that last one and one-half hours and the other that last for four hours, the rest lasted an average of two and one-half hours.

In Edinburgh too, the majority of the women were interviewed on only one occasion. However I interviewed four women twice and one woman thrice. This made a total of 18 interviews in Edinburgh. The main reason for conducting interviews on more than one occasion was the time that the respondents spent questioning and talking about my study and themselves and before the actual interview began. A secondary reason was other appointments, which meant that the women could only complete part of the interview, and a new date and time had to be set up.

Bearing in mind the confidentiality requirements, all respondents were interviewed in a place that was suitable to them. The majority of the interviews were conducted in a room provided by ARCON and Solas. In ARCON the room had a desk and chairs, and the respondents and I sat across the small table, with the tape recorder in the middle of the table so that both our voices could be effectively recorded, in spite of the varying background sounds. The seating arrangements in Solas were informal and comfortable with an occasional background sound. A few interviews in Edinburgh were set-up in the premises of Positive Voice (a non-governmental organisation for People Living with HIV/AIDS) by respondents who were also



service-users of Positive Voice. All the settings were comfortable and offered privacy, making them a conducive place to conduct interviews.

In both cities some interviews were conducted at the homes of my respondents or at my home. A few women in Bombay selected their own homes because of convenience: saving them the time and energy of travel; others chose my home in order to ensure privacy. While women in Edinburgh also chose their own homes for convenience, those who chose to be interviewed in my student flat did so either because of convenience or because they were happy to meet “some place different.”

Two interviews in Bombay were conducted in my respondent’s one-room homes. Starting both these interviews took longer than expected, because one of them being in a *chawl* (a large lodging house, offering cheap basic accommodation, often to several families on the same floor) meant that neighbours or family members wanted to welcome me and offer me food and drink before we could get privacy to start the actual interview. The other interview took time to start, because the respondent had to finish cleaning the wheat for her son to take to the mill. I helped her with the sieving of the wheat. This hastened the process of the cleaning and the departure of her son from the house, and gave me a chance to build a rapport with her. The interviews in my home in Bombay were conducted in the privacy of my study.

One interview in Bombay was held at a friend’s home. This was because the respondent did not find it convenient to travel to either ARCON or my home, nor was it possible for privacy reasons to conduct the interview in her home. My friend’s home was chosen because it was ideally located for my respondent, a few minutes away from her home, and because of the privacy it offered.

In Edinburgh the interviews at the respondent’s homes were conducted in their living rooms, and in my room in my student flat. Privacy was ensured in all settings; however the degrees of background sounds varied from place to place.

I began all my interviews by asking women if they were comfortable and ready to start. Depending on the location of the interview, I offered women a drink of water or tea or coffee before we began. In Bombay, after most of the interviews at ARCON, I invited women, and on one occasion the woman, her mother, and her child, to a nearby restaurant for tea and snacks or for lunch. When interviews were conducted at my home in Bombay, I offered women tea and refreshments before the interviews. In Edinburgh I generally invited women for a meal before we started the interviews, either at Solas or at my home. I believe the time we spent eating together helped us to build a rapport. When I visited the homes of women in Bombay and Edinburgh I took a small packet of assorted sweets, nibbles, and fruit.

I spoke to women in Bombay in three different Indian languages: Hindi (the national language), Marathi (the local language of the state Bombay belongs to) and Gujarati (the local language of a neighbouring state, Gujarat). I am fairly fluent in all three languages, but not being a native speaker of any of the three, at times I re-worded questions to make sure I was understood. On a few occasions I had to ask respondents to repeat certain words or concepts that I had not understood, for example, the word barren or infertile.

I began all my interviews by thanking women for participating in my study and briefly outlined the aims of the study. I then invited them to read the letter requesting them to participate in the study, and the letter of consent. When the consent form was signed, I asked them if they had any questions to ask me at that stage, and reminded them that they could seek clarification at any point during the interview. I then proceeded to ask questions. Throughout the interview I listened carefully to what was being said and rephrased sentences, clarified doubts, and asked for meanings of words when I was unclear. Equally important was the observation of women's non-verbal behaviour. This gave me the opportunity of discussing certain issues, for example, when a woman seemed uneasy about answering, I would ask her if she was feeling that way. Often that led to asking her why she was feeling that way and whether we could discuss it at the time or later.

Interviews were generally in the form of conversations. I tried to ensure that I watched and limited my participation in order not to lead the interviewing process. I used non-verbal and verbal encouragers and paralanguage (Adler et al. 1995) such as smiling, nodding my head, saying yes or no, putting my hand on their shoulder or touching their hand when they were upset or crying. When there were periods of silence, I usually gave the women time to gather their thoughts and feelings before I said anything. I respected their need for silence at times by just being attentive but silent myself. Throughout the interview, I tried to simplify and clarify my questions to avoid misinterpretations on the part of the respondents (Kvale 1996). Additionally, I used probes to deepen the response to a question, to increase the richness of the data being obtained, and to give cues to the respondents about the level of response that was sought. This was done through direct questioning of what had just been said, for example, "Could you say something more about that?" Sometimes, a mere nod, or "mm", or just a pause were used to signify to the respondents to go on with their description. Repeating significant words of an answer can lead to further elaboration (Kvale 1996).

When the pre-arranged time to end the interview came close, I usually discussed how much longer we would need and what they felt about spending that time. Some women decided to end the interviews at that stage, while others were happy to finish on the day itself. At the end, I asked all women whether they had any questions or wanted to make any comments. This period allowed the respondent and me to engage in a process of debriefing and relaxation that was needed at the end of emotionally intensive interviews.

**Experiences While Collecting Data.** To collect data, I utilised a combination of elements from Massarik's (1981) categories of interviews: the element of creating a genuinely human relationship from the "rapport interview;" the element of an intensive process of thorough exploration from the "depth interview;" and the element of mutual trust from the "phenomenal interview." I took several steps to ensure that the interviews conducted in this study were based as close to his interviewing techniques as possible. To begin with, I made every attempt to present

myself to my respondents as an individual whose main interest was to understand their experiences from their point of view. I stressed on the fact that the process was a conversation between equals, in which both of us were equally engaged in a process of understanding. I emphasised that there was no right or wrong, or good or bad answer.

At the very outset, I aimed to establish a relaxed atmosphere, by developing a personal rapport, and asking the women to call me by my first name. In Bombay however, a majority of the women called me *didi*, *tai*, or *behn*. All of these words mean “older sister” and are generally used as terms of respect. I also stressed that I would try to answer questions they might have, even if these were not directly related to the research. What is more, women were given the right to withdraw from the interview process from the start, if and when they chose, without having to provide an explanation for their decision. Although mutual trust usually takes some time to develop, I hoped that the guarantee of anonymity and confidentiality they received from me would create the basis of an open and trusting relationship.

All the respondents were willing and vocal participants, however, some women from both countries were initially anxious about confidentiality issues. Women in Bombay were hesitant to share biographical details that revealed their identity, especially their second names and their addresses.

A few respondents from Bombay and Edinburgh started giving me details about their lives even before I began asking for them. I believe that the women in Bombay may have begun this way, because this was the first time they were being interviewed and were unaware about the process of interviewing; it also could have been a reflection of their eagerness to share their accounts. Some women in Edinburgh too, who reported having participated in several earlier interviews, also began by giving their biographical information and details of how they became positive. Here too, this could have been a reflection of their willingness to share their accounts. Two women from Edinburgh seemed to have told their stories quite often, because they almost gave an impression of reciting pieces that had been well rehearsed. It is possible that

these women had participated in previous research that required them to relate their histories with HIV/AIDS.

The interview was designed in such a way that it guided the women to narrate their accounts from the time just before they discovered they were positive, to the period that followed that revelation, up to the time of the interview. The act of recollecting their accounts in a chronological order seemed to facilitate the flow of the narration and provide a rhythm (Vaughan 1986).

As a researcher I was struck and humbled by the genuine effort some women made to participate in the interviews. One woman in Bombay who had at the time recently lost her nine year-old daughter to AIDS, travelled five hours to and from ARCON to participate in the interview. I had offered to go to her home, but she insisted that I should not take the trouble of travelling "in the terrible heat." I was struck by her kind attitude and gentle manner toward me. Padgett (1998) refers to the kindness extended to well-meaning researchers as the "kindness of strangers". One woman in Edinburgh made an effort to meet up on three separate occasions to complete the interview, because she was too weak physically to talk for long periods of time.

The respondents used a variety of tones and manners to narrate their accounts. Most women spoke very softly and slowly throughout the interview. I believe for many, the act of recalling and describing painful events to a relative stranger for the first time, contributed to their rather soft and slow pace. It appeared as if the emotions of past memories were relived during the interviews. At times, the intensity of the emotions being recounted created a very emotionally charged atmosphere for both the respondent and myself; some women broke down and cried. Some respondents followed the grief of their tears with laughter or a smile; others expressed anger in their voices and words. Yet others used a despondent, confused tone of voice and slouched in their chairs. One woman in Bombay repeatedly bit at the end of her handkerchief as she cried and spoke with anger and frustration about her "cruel in-laws". Another woman in Edinburgh kept biting her lip in an attempt not to cry. Crying seemed to provide a catharsis that helped relieve the intensity of their



emotions. When the women cried, I tried to reassure them either by holding their hand or comforting them with a pat on the shoulder. At other times I reassured them with words to convey my empathy, listening patiently to their accounts and telling them that I understood what they were feeling. I also gave women the option of taking a short break, to calm them or to provide them with some respite from the strong emotions. Some women took the break; others said they did not need it.

Through affirmation and reassurance, a greater sense of control, an enhanced will and hope and an emotional benefit from catharsis is experienced (Harvey et al. 1990). Some women reported that they felt much better after they had cried. One woman used the metaphor of her pain being washed away by her tears. In general, the women seemed to be more relaxed and calm after they had cried. I sought to keep a critical distance (Padgett 1998), although, there was one instance when my professional barrier momentarily broke down and I was moved to tears listening to an account of a woman losing both her husband and child.

The process of conducting these interviews was demanding at times, because they (the interviews) focussed on the deeply troubled lives of the respondents. When the women narrated their accounts, inevitably the act of telling and recreating their story made them relive their pain, loss and sorrow, in spite of the time that had gone by (Vaughan 1986). One woman from Edinburgh, who was interviewed at her home, became rather agitated when she recalled the pain she had experienced when she was raped and her neck was slit. She showed me clips of the videotape and photographs that the police had taken at the time. She then started pacing up and down in her room and spoke with great anguish about heroin and the abuse she had experienced. She borrowed my pen and started writing behind my interview guide, scrawling the words "a living hell," with all her strength. I listened to her and allowed her to express her feelings and articulate her pain. At the same time, I was very conscious of the level of intense emotions that the interview was eliciting from her and tried to calm her down. My response to her shifted from being a research interviewer to a social worker (the dilemmas that arise from this conflicting role are discussed more fully in the section on ethics). This heightened emotional state lasted for over ten



minutes. Seeing her discomposure, I suggested that we continue the interview another day. Additionally, I was running out of tapes (not having envisaged that the interview would last more than three hours, I had carried only one spare tape). However this did not dissuade my respondent, who quickly produced two of her own and said she was unwilling to stop the interview. I asked her if we could take a break and have some tea. A drink of Vodka that she helped herself to seemed to calm her marginally. We continued with the interview for another one and one-half hours, bringing the total interview time to six and one-half hours. I ended without asking her the last question about testing, because it was past 9 pm and issues about my own safety took precedence.

These experiences highlight the feminist qualities of my research approach. In my efforts to understand the experience of HIV/AIDS from the women's own perspective, I developed relationships with my participants that were more egalitarian and mutual than what would be expected in a traditional research paradigm.

### **Researching Sensitive Subjects**

Sensitive subjects are those that seem either threatening, or contain an element of risk in some way (Renzetti and Lee 1993) and address some of society's pressing issues (Sieber and Stanley 1988). Moreover, they include areas that are private, stressful or sacred, or potentially expose stigmatising or incriminating information (Lee 1993). Researching the lives of women with HIV/AIDS may do both of these things and therefore have the potential to harm individuals who are already vulnerable. Further, the study of HIV/AIDS is a highly emotive subject, with emotional implications for both the respondent and the researcher (Bourne 1998).

Researching a sensitive subject obliged me to build an ethical relationship based on respect, trust and "cultural sensitivity." My knowledge, skills, and values enabled me to gain access to the respondents, to learn about their way of life, and to communicate in ways that they regarded as significant (Sieber 1992). By ensuring confidentiality and asking questions about painful experiences judiciously (Padgett

1998) I built a relationship in which minimum distress was caused to the respondents during the interview process.

While conducting some of my interviews, I experienced a minor ethical dilemma about the role I needed to play. At times, the interview resembled a therapeutic interview rather than a research interview. In sensitive feminist research, respondents are invited by the researcher to share their thoughts by eliciting their core emotions, and by listening to them (Weiss 1994). These elements of the interview resemble a therapeutic interview (Birch and Miller 2000). One of my respondents in Edinburgh became very disturbed while recollecting traumatic experiences from her past, and needed support to be calmed down. Being a social worker, I felt naturally inclined to play a therapeutic role, but kept reminding myself of my role as researcher. I tried balancing the situation by reminding her that she was free to stop the interview, at the same time, assuring her of my support if she chose to continue (Massey 1996) thus aiming to develop an “emotional middle distance” (Weiss 1994, p.123).

Although the principal ethical focus of all research lies in ensuring no emotional harm to our respondents, an awareness of the emotional issues that arise for the researcher are also important, so that they do not interfere with the study (Padgett 1998). Young and Lee (1996) argue that the role that emotion plays in the everyday life of the researcher has not been given adequate recognition. The process of interviewing positive women, introduced both the respondents and me to a kaleidoscope of emotions (Bourne 1998). I found that these emotions were both challenging and rewarding; thus I experienced a mixture of pain and privilege.

Researching lives that had experienced pain, loss and some form of trauma was demanding. I often felt exhausted after an interview. I believe that this tiredness was not so much the result of the stress that arose from the demands of the research process; rather it was the strong emotional response that women’s stories evoked in me. At times, I felt depressed by all the pain and emotional trauma recollecting by my respondents. During the process of transcribing and transcription (as pointed out earlier), the voices of the women often resounded in my head. Nearly two and a half

years later, when I started working on my analysis, and was absorbed in hearing the tapes and reading transcripts, the voices resounded within me once again. The pain and loss expressed by my respondents resounded at times in my consciousness. It brought back painful memories of loss that I had experienced in my own life and worse, pulled me into an unhealthy pattern of anticipatory grieving.

However, it must be stressed that throughout the process, there were innumerable instances of hope emanating from the women, who had handled their difficult lives so courageously and resiliently. This hope made me feel optimistic and renewed my faith in the strength of the human spirit. I felt privileged that they shared their accounts of living with HIV/AIDS with me.

### **Recording Data**

The presence of a tape recorder made two women in Bombay rather anxious initially. One woman became extremely fearful and wanted to leave the interview when I asked her name and address. She said that she did not expect to be asked questions that would identify her. She also said that if anyone in her community discovered that she was positive it would be disastrous for her. She said: "that will be the end of me". I spent over quarter of an hour re-explaining issues of confidentiality, the letter of consent that she had just signed, the purpose of my study, how the information on the tapes would be utilised and how the tapes would be inaccessible to anyone apart from myself. When she was suitably reassured, I asked her whether she would like to continue with the interview and she replied in the affirmative. Nonetheless to further reassure her, I told her that I would not ask her for her address. The immense relief on her face was unmistakable and we continued the interview. However at the end of the interview she felt confident enough to ask me to contact her when I returned to India, and urged me to write down her address.

The other respondent also became rather uneasy at the very start of the interview when I was testing the volume and the tape and she heard her voice. She said that she felt very embarrassed to hear her own voice, and that it did not sound like her. She urged me to write down her responses rather than taping them. I spent time to explain

the purpose of taping the interviews, a little bit about the distortion of the sound while taping, the impossibility of manually writing out each of her responses and the fact that no one apart from me would be hearing the tapes. I also reassured her that she actually sounded good and that I was genuinely keen on speaking to her. She agreed to me using the tape recorder and the interview was successfully taped. It was a relief that after the initial discomfort, both respondents seemed to relax and were not inhibited by the tape recorder.

Although I had envisaged that recording the interviews might restrain some women in sharing their experiences, especially in the Indian context, I believed that the benefits of a more accurate and complete collection of data outweighed this problem. Moreover, since none of the three Indian languages were my first language, taping the interviews insured that I accurately got down the actual words spoken at the time. The research notes that I maintained throughout the process were also important elements of data collection. I made it a point to jot down my thoughts, feelings, experiences and reflections as soon after the interviews as possible. These notes aided me through the process of analysis. They provided a stimulus to recall the non-verbal communication and other observations that I had made immediately after the interviews, thus enhancing the trustworthiness of my study (Breakwell 1990).

### **Analyses and Interpretation**

The aim of the data analysis was to understand the lives of the 27 positive women from Bombay and Edinburgh; and the focus was their experiences as recounted by them, preserving the richness and uniqueness of each of their lives.

There is no single approach to qualitative data analysis; qualitative researchers tend to follow what works best for the data they possess (Padgett 1998). In the course of my analysis, I tried to construct meaning of what the women had told me about their lives and what I was able to closely observe about them during the interviewing process. Being a woman, I inevitably shared a part of the social world of my respondents (Hammersley and Atkinson 1995). Feminist researchers stress the social construction of the research encounter as a lived experience, which is reflected in the

use of the personal pronoun throughout the study (Oakley 1981). Qualitative texts routinely use a more informal style of writing (Padgett 1998).

Taking a reflexive approach to data analysis presented me with the challenge of balancing the voices and views of my respondents, while acknowledging my role in shaping the research process. Throughout the analysis, I adhered to the qualitative, phenomenological, feminist perspective by listening to my respondents and understanding their lived experiences in and on their own terms (Denzin and Lincoln 1994) while remaining reflexive about my role. At times, while writing, I had problems maintaining a balance, or keeping a critical distance and yet reflecting the respondent's humanity (Padgett 1998).

The element of time is an essential decision in qualitative research (Padgett 1998) and structures the presentation of the findings (Weiss 1994). I chose to present the findings as a diachronic report, because I wanted to study the life experiences of positive women through the stages that mark the progress of HIV. Presenting the findings this way gave the study a built-in story line (Weiss 1994).

The process of data analysis undertaken by me is described as a series of specific, but overlapping, stages. Although described as a linear process, it was more cyclical and required revisiting the original transcripts and at times, even rehearing the tapes.

### **Transcription and Translation**

Word-for-word transcriptions were made for all 27 interviews. Verbatim transcriptions are a crucial ingredient for detailed and reflexive analysis, because the transcripts and the researcher's analysis of them form the basis of developing theory (Glaser 1992). The process of transcription was time consuming and laborious: On an average I took between 10 to 12 hours to transcribe a two-hour interview in English and 14-15 hours to transcribe interviews from the Indian languages. Since the interviews conducted in Bombay were in Indian languages that had a different script, they had to be first transcribed manually by hand, translated and then

incorporated into the computer database. The interviews in Edinburgh were transcribed directly with the use of a PC word processor.

The interviews in Bombay were conducted in Hindi, Marathi and Gujarati. I began by transcribing the Hindi and Marathi interviews using the *Devanagiri* (the script used in Hindi and Marathi) script. Since I was unfamiliar with the Gujarati script (which is an adaptation from the *Devanagiri* script), I transcribed the Gujarati interviews using Roman Alphabets. I found that although I possessed fairly satisfactory skills in both languages, the process of transcribing in the *Devanagiri* script became torturous and too lengthy. I therefore switched to transcribing all the interviews using the Roman alphabet. This made the process comparatively simpler and faster.

While doing a verbatim transcription of the Edinburgh interviews, it was interesting to observe that my respondents sometimes said things that were grammatically disjointed. At times, I noticed that, likewise, my sentences were less than perfectly formulated too. It made me realise that often the spoken word relies on several non-verbal, unspoken things to be conveyed, thus conveying an apparent lack of coherence when written.

Through the process of transcription, I began to develop an empathetic grasp of each respondent's story. The hours spent transcribing interviews gave me a feeling of reliving the interviews. Some of the accounts recalled by women were traumatic, and lingered on in my consciousness even when I was not transcribing the tapes: the women's voices seemed to go on in my mind, especially when I was trying to fall asleep at night. Words in Scots, such as, *doon*, *ye*, *yer*, *aye*, *ken*, and *bairns* used by some women in Edinburgh seemed to resound in my brain.

The transcripts of my interviews needed to be translated from Hindi, Marathi and Gujarati into English. My first language is English, and translating the interviews was a challenging process that tested my skills with the Indian languages and with English as well. I tried to remain as faithful to the meaning of what women were



saying. At times I discussed the meanings of certain words and sentences with a friend who was a native speaker of Marathi and a very fluent speaker of Hindi, to make sure that I had understood the meaning of what the respondent had said.

Initially I did a literal translation, but on re-reading the translations, I found that they sounded disjointed and at times did not make sense. Certain sentences that were understandable, and made perfect sense in the language of the respondent did not ring true in English. I found that similes and metaphors did not lend themselves to accurate translations. For example, one woman recalled in Gujarati that when she heard she had been infected by her fiancé she broke into a sweat. However a literal translation from Gujarati would read as “I became water-water hearing that” (*hu to paani-paani thay gay ee sambhaline*). I therefore started translating the interviews in my own words, trying to keep as close to the essence of what was being said, so as not to sanitise the data. This meant that some of the cultural flavour of the expressions and words used was reduced. Something anecdotal about the effect of translation that I discovered during the process of analysis: as I read and re-read the transcripts of the women in Edinburgh, I could clearly envisage and hear the women’s voices in my mind’s eye. The same thing did not happen with the translated interviews; I needed to go back to the recording to get that sort of sense.

There are several arguments in the literature related to literal, versus free translations. Honig (1997) points out that a literal translation could perhaps be seen as doing more justice to what the respondents have said and reveal the mentality of the respondents to foreign readers. Wolcott (1994) also argues that literal translations enable readers to see for themselves what respondents look like. Birbili (2000) on the other hand argues that this view to literal translations could diminish the readability and understanding of the text. However, she cautions against free translation. She suggests that editing quotations involves the risk of misrepresenting the meaning (Rubin and Rubin 1995). Etherington (1999) also touches on the aspect of meaning in a free translation. She suggests that the translator filters the meanings produced by the respondent, thus giving the researcher more control over what is being said. Sperber (1993) supports the free translation. He points out that relevance of the text

is exchanged for faithfulness to the text. Albeit the inherent difficulties in both stands, I cautiously utilized the free over the literal translation because I believed that this form of translation allowed a clearer understanding of what was being said, and therefore was more faithful (Sperber 1993) to the meaning of what the women said. Getting the meaning of what they say is more important than getting their exact words (Stake 1995).

The problems of translation were not only technical; another aspect was related to the socio-cultural differences in meaning (Hubert et al. 1998). Both the women and I used phrases that were imbedded in our own thought processes and socio-cultural backgrounds. For example, in one the first few interviews, I referred to a woman's husband visiting a sex worker. I discovered that the use of the term that had seemed like the logical translation, offended the woman and that she preferred to refer to the event euphemistically as "he had gone out." I noticed that other women too used this phrase, or ones like "visiting a business woman."

Another aspect that is relevant to my experiences in translation is the difficulty in conceptual equivalence or comparability of meaning (Deutscher 1968), which calls for the translation of culture (Abrahamian 1993). For example, three women from Bombay spoke about their feelings of emptiness, futility and finality when the *tikka* (a mark of marriage, usually a vermilion powder applied to the forehead or in the parting of the hair) needed to be wiped from their foreheads. Neither a literal nor a free translation of the women's words would express the significance of the social status accorded by the *tikka*; nor would the significance of widowhood, stigma, futility, and finality expressed in relation to wiping the *tikka* be understood without a translation of the culture in which it lies embedded.

Philips (1960) argues that it is difficult, if not impossible to achieve a comparability of meanings, because language carries with it a set of assumptions, feelings, and values that the speaker may or may not be aware of but that the researcher, as an outsider, usually is not. However, Abrahamian (1993) points out that the researcher being both an insider and outsider can partly resolve this problem As demonstrated

earlier, I believe that as researcher I fitted the description of both insider and outsider, and possessed an intimate knowledge (Frey 1970) of the women's culture that enabled me to achieve a comparability of meaning when translating their words into the English language.

After transcribing and translating of one interview each from Bombay and Edinburgh, I reflected on them. My aim was to develop an understanding of the significant ideas that were emerging from the interviews. I began the process of data analysis and search for meaning, because in qualitative research the process of data analysis should ideally begin before data collection has been completed (Glaser and Strauss 1967). However, because of my intense involvement in collecting data from respondents in Edinburgh and the transcription and translation of the Bombay interviews, I was unable to sustain the process of data analysis at the time. Although I tried to ensure that I listened to the tapes within a day of the interview, and read the transcripts soon after they were transcribed, at times highlighting themes as they emerged in the process of my reading, I found data building up and many weeks elapsed between periods of concentrated analysis.

### **Conceptualisation: Search for Meaning**

On completion of all transcriptions and translations, I immersed myself in the process of analysing the data. I utilised van Maanen's (1990) selective reading or highlighting approach. This involved re-reading the transcripts, sometimes as many as four to six times. In some instances, I listened to the tapes to ascertain the manner in which the women had recalled something, and added a note to the transcript. Sentences that seemed to explain the experiences and phenomenon of living with HIV/AIDS were highlighted.

The mass of information began to make sense in a distinct way: similar and dissimilar themes started to build up. However, I needed a conceptual framework to help guide me through the patterns that were emerging, some kind of map that would lead me through the unmarked journey of analysis (Cole 1994). Therefore I used flow charts to map the themes in the three stages that mark the progress of the

illness: the pre-diagnosis stage, diagnosis and post-diagnosis that included the present when women were interviewed. Themes were further categorized into sub-themes, leading to the refining of themes, until I reached a point of “data saturation”, that is, when no new themes or sub-themes emerged (Padgett 1998). Through this process I discovered concepts that hitherto I had not thought of. For example, the concept of self-effacement: I found that women in both Bombay and Edinburgh were self-effacing about their own needs compared with those of their children. In addition, women in Bombay were self-effacing in relation to their husbands. This process enabled me in conceptualisation (Hammersley and Atkinson 1995) or making sense of what was going on in the scenes documented by the data, and to locate meaning in the data.

Initially I attempted to analyse the data mechanically with the use of the computer software programme NUDIST. However, I found that the process of inputting the data and becoming proficient with the programme itself got in the way of hearing the women’s stories, and so I abandoned this effort. Although the manual process was time consuming, it was advantageous because deeper explanations and insights, patterns and a holistic picture emerged.

### **Developing Themes and Issues**

I followed a simple inductive process of analysis to organise themes and sub-themes from the data. This enabled me to address the central research question: what were the life experiences of women with HIV/AIDS, keeping in mind the philosophical perspectives and methods that underpinned my research.

Varied elements were considered in the development of data into themes and sub-themes. Data that were found consistently across a range of interviews constituted a theme. Conversely, data that was atypical or unique also led to the development of a theme. The goal was to uncover as many distinct themes as could be found in the data. Most of the themes were empirically driven, allowing the data to speak for itself. Some additional themes were developed from theory using categories that have already been established, for example, Kubler Ross’s Stages of Grief (1969).

This was a stage marked with experimenting and exploring, trying out themes and sub-themes.

The themes that emerged as important were discussed with my supervisors to ensure that my “decision trail” was meaningful. I returned to the transcripts to draw quotes that illustrated the themes, looking for similarities and differences both within each context and between each context that described the life experiences of women with HIV/AIDS. Identifying the themes in each woman’s story helped me to see consistent patterns that were emerging from the data (Fetterman 1989). The patterns pieced together to form a mosaic out of the accounts, leading to the development of a synthesised life story (Denzin 1989a).

The patterns of demographic, bibliographical information that emerged from the women’s accounts, along with the patterns that emerged from substantive psychosocial aspects of their accounts, led to the development of specific assertions for each of the three time periods included in the study.

## **Assertions**

The process of reflection and interpretation of the underlying themes patterns and issues allowed for the drawing of a number of conclusions. Those found to be meaningful, and believed to answer the research questions under investigation, are restated as assertions (Erikson 1986). These assertions are logical groupings of the issues based on the observations and understanding of the researcher, gained over the course of the study, as well as on the findings and assertions of other researchers (Stake 1995), and on the empirical data discussed in the findings chapters.

## **Ethical Issues**

Researchers have a duty to take an ethical perspective to their research (McBurney 1994), and qualitative research seems to be an approach that often engenders ethical concerns (Ely et al. 1991). Given the sensitive and cross-cultural aspects of my

study, issues of confidentiality, informed consent, trust and reciprocity, and emotional well-being were addressed within an ethical framework. It also helped to ensure that I adhered to the three important scientific concerns that should govern all social research: beneficence or the maximizing of good outcomes while minimizing unnecessary risk or harm; respect or the protection of the autonomy of respondents; and justice or the assurance of reasonable, non-exploitative, and carefully considered procedures with fair distribution of costs and benefits (Sieber 1992). By choosing a topic that had the potential of improving the lives of some people, I hoped to fulfil my ethical obligations as a researcher who cared about human concerns.

### **Confidentiality**

The need to take the utmost care about confidentiality is a paramount consideration in HIV-related research. This is because of the potential for serious discrimination, stigmatisation and general distress that could occur if details of a respondent's HIV status were to be revealed to others (NHMRC 2001). In all my contacts with potential and actual respondents, I stressed that the information they would provide would be treated with the utmost confidentiality. Additionally, at the beginning of each interview, I reassured my respondents that confidentiality and anonymity would be protected throughout the process. Irrespective of where the interview took place, I tried to ensure confidentiality and privacy. As I have outlined earlier, there were instances when the interviews were conducted in the homes of respondents, in Bombay. In these cases, it took some time and effort to ensure privacy. I took care to ensure that all personal details divulged were secure and that no identifiers were used on any publicly available material. To protect the anonymity of the respondents, I gave each of them a pseudo-name. Confidentiality was also seen as crucial when using direct quotes in writing the thesis, and names of hospitals, areas where respondents lived, or any other identifying details have been carefully removed.

### **Informed Consent**

As discussed earlier, participation in the study was entirely voluntary, and each respondent was made aware that they could withdraw from the process at any point if



they so wished. However, none of them opted out of the process. All respondents voluntarily signed the letter of Informed Consent.

### **Reciprocity and Trust**

The principles of reciprocity and trust were important ethical issues in my study. Reciprocity is the practice of giving in return for what one has received. As a researcher, it was important for me to consider giving something back to my respondents. There were two aspects to this process of reciprocity that I engaged in. Firstly, the ethical issue of financially compensating some respondents from Bombay arose, when I realised that my very first respondent lost a day's wages when she agreed to speak to me. Respondents were therefore given compensation equivalent to travel expenses and lost wages for participation in the study. All the respondents, except for two, accepted the money.

The second issue of reciprocity involved trust. It arose from the fact that I wanted my respondents to begin to trust me and "open up" to me. The element of trust between my respondents and me was crucial in gathering honest, reliable accounts (Lofland and Lofland 1995). This meant that I had an obligation to reciprocate by sharing details about my life when they sometimes questioned me about myself. I answered their questions as briefly and honestly as possible. In the process of developing a reciprocal atmosphere of trust, I was conscious of not shifting the focus from my respondents to myself. I believed that the act of recalling their account gave them a chance to paint a meaningful and coherent picture of their past and present life, and an opportunity to glance at their future (Birch and Miller 2000). Sometimes, when a respondent brought up something we had in common, I spoke briefly about the similarity of my own experience. I endeavoured to be reciprocal by being open and accepting in all my interactions, and by being an empathetic listener.

Further, I tried to reciprocate by providing information that was requested after the interviews. Almost every respondent in Bombay asked me hopefully about a "miracle cure" for HIV/AIDS that was guaranteed to cure them. They had heard that such cures existed "abroad," in the land where I studied. I talked to them about

Combination Therapy, its costs and problems some women had experienced when they tried it. I also explained that no miracle cures existed and urged them not to believe any unscrupulous persons who may try and take advantage of them. One woman was very persuasive and begged me to send her some medication from outside India. She said that her brother would take a loan, if needed, to repay me. I had to gently explain to her that these medications were not available over the counter. I did not go into details of just how prohibitive the costs would be, because it could have made her feel worse.

All the women in Bombay and Edinburgh had my address on the letter I gave them I requesting them to participate in the study. However, some women in Bombay asked for my address in Edinburgh so they could write to me, which I did give them. Some women in Bombay wanted information about legal aid, or asked me to find them jobs as domestics. I did give them names and addresses of people and organisations they could contact for help.

### **The Power of Stories**

Through the process of interviewing the women, the idea that telling one's story was an empowering exercise continually struck me. The majority of the women were totally engrossed in the act of telling their story, and likewise I too was absorbed in their stories. I realised then how important it was for them to tell their story and for me to listen, especially in the face of the vulnerability they experienced. For some, just telling the story seemed to be a cathartic experience, which provided its own reward (as in the case of the Indian women). For others, knowing that their stories could hold some meaning for others (as with the Edinburgh women) made sharing their experiences worthwhile.

The power of telling one's story is tremendous (Kilty 2000). The process of recounting one's life history seems to contribute greatly to the narrator's personal sense of well-being and integrity, largely due to the fact that the listener makes an empathetic attempt to understand the life story (Cohler 1994). Moreover, being able

to give a coherent and meaningful account of one's life is a crucial aspect of resilience in the face of adversity (Cohler 1991).

The majority of the respondents were fully involved in recollecting and sharing their accounts. A few women in Bombay observed that they found it easier to share their experiences with me rather than with their family or friends. Most of the respondents from Bombay and some of the respondents in Edinburgh told me that it was the first time they had recounted their life experiences and confided to a stranger. Vaughan (1986) had a similar experience. She found that her respondents were comfortable with the process of confiding in her, because she was someone from outside their daily lives. She argues that when respondents accept an invitation to be interviewed, they accept an invitation to share their personal experiences.

The appreciation expressed by the women at the end of the interviews indicated that there was an unmet need for opportunities to discuss their lives. Even those respondents in Edinburgh, who had the previous experience of sharing their accounts, expressed a strong feeling of gratefulness. Many of the respondents from Edinburgh expressed the hope that the information they shared would be of help to others and showed an interest in reading the study once it was complete. Some women said recollecting their accounts were hard, but they were willing to do this if it was of help to somebody else. Others expressed the sentiment that they were privileged to share the gift of experience and have their voices heard.

On the other hand, the majority of women in Bombay did not express any hope of their accounts being helpful to others, nor did they show any interest in seeing the study when completed. However, there were a few exceptions. For example, one woman said that she hoped that some women reading her story could gain strength from it. I believe the attitudes of women in Bombay and Edinburgh towards the final effect of the study differed greatly because of a number of factors that outline the differences between the two groups. The women in Bombay had tougher lives, and had to struggle harder for their day-to-day needs than did the women in Edinburgh, whose hardships did not include worrying where their next meal came from, for instance. Another crucial difference was that the women in Bombay knew that the

study they were contributing to was going to be written in English, which to them was a foreign language. Their literacy levels were much lower than those of the respondents in Edinburgh. Also, they had no previous exposure to academic exercises such as research, and therefore seemed further removed from the study than did their Edinburgh counterparts. Their reality was very much a here-and-now reality, and my study and what it might accomplish seemed remote to them. Conversely, the women in Edinburgh were more exposed to the concept of research and understood better what the outcome of it might be. Unlike the Bombay women, they were not in a position of having to struggle for their daily needs, being much better off financially.

Finally, Kilty (2000) argues that individuals can change themselves and others by telling stories of their illnesses. She points out that illness stories are therapeutic for tellers who have a real opportunity to be heard and to hear themselves, and to step outside of themselves and observe who they are. These stories are empowering for persons with similar illnesses because it helps them to know they are not alone in their suffering. For the listener (researcher), as suggested in the feminist perspective, they are enlightening, because they provide insight and a vicarious lived experience of the teller (Oakley 1981). These stories are not the objective telling of the facts; rather, they are the women's "remembrances, retrospections, and constructions about the past" (Sandelowski 1991, p. 165). She suggests that such stories are located in a hermeneutic circle of interpretation and reinterpretation, and are therefore likely to change over time with each telling.

Thus, the power of the story lies in the meaning of the experience recalled in the story, and the very act of telling one's story can be a transforming experience. For my respondents in this study, making sense of their complicated and often tragic stories seems to have been a healing and ultimately encouraging experience.

## Conclusion

This chapter has described the complex process of developing the methodology for my study. My goal was to create a qualitative study that would capture the experience of positive women as they deal with HIV/AIDS in their daily lives. The study presented unique challenges because of the sensitive nature of the topic, and because of the fact that I was working within two distinct cultures. Further, in taking an explicitly phenomenological perspective, I encountered the many dilemmas associated with trying to make sense of another person's experiences without imposing too much of my own expectations and beliefs. Finally, I was faced with the necessity of creating some sort of conceptual scheme for understanding the great volume of data generated by 27 lengthy interviews.

The case summaries in the next chapter represent the first step toward understanding the essence that was distilled from the interviews and the transcripts. The goal is to present each respondent and to illustrate the key elements of her situation. These summaries will serve as a backdrop for the substantive material to be presented in later chapters.

## CHAPTER 4: THE RESPONDENTS

### Introduction

This chapter provides a brief description of the accounts of each respondent through a case summary. These case summaries offer an introduction to the respondents, rather than a definitive account of their lives. They touch upon the respondent's biographical information, the advent of HIV/AIDS in their lives, and upon the different ways in which the respondents recounted their life experiences. In addition, they also explore core ideas that are central to the respondent's narration and provide a vicarious experience (Stake 1995) of the complexities of their lives. In some cases one-core idea was adequate to reflect the essence of the respondents accounts. For others more than one was required to capture the essence (Wolcott 1990). The patterns that emerged from the biographical information of the respondents are discussed in this chapter. "At the time" refers to the year 1999 for the interviews done in Bombay, and to the year 2000 for the interviews done in Edinburgh.

The respondents narrated their life experiences movingly, with strong emotions that ranged from cheerfulness, enthusiasm, courage, strength, resoluteness and humour, to sadness, pain, anger and confusion. They seemed to have an empathetic grasp of the questions that were asked. Despite their social disadvantages, they possessed an insightful and powerful understanding of their own lives.

### Positive Women from Bombay

#### **Respondent 1**

Aarti (B.1), age 27, lived in Bombay. She narrated her story very slowly and softly. Her eyes reflected a sense of deep pain throughout the interview. Aarti completed two years of education after high school and was unemployed. She worked for a computer assembling company, but discontinued her job six years ago, when she became very weak during her pregnancy. Aarti lived with her husband and daughter



in a rented one-room accommodation. She had been married for over 6 years, and her husband, a semi-skilled worker, supported her financially. Their 5-year old daughter was in nursery school at the time of the interview.

In 1997, both Aarti and her husband discovered they were HIV positive, after their daughter became unwell and tested positive. Aarti recalled that her child's diagnosis had been very painful and the fact that she was responsible for the transmission was unbearable to accept. Aarti believed she contracted the virus through her husband, who probably contracted it from a sex worker. Aarti and her husband were HIV asymptomatic at the time, but their child had symptomatic HIV. Aarti was uncertain about what the future would bring and feared the worst for her child.

## **Respondent 2**

Aditi (B.2), age 31, also lived in Bombay. She was upset throughout the interview and went from being angry to bursting into tears. Aditi completed two years of education after high school and was unemployed at the time. Earlier she had worked in a doctor's dispensary for 11 years, after which she worked as a beautician's aide in a beauty parlour. Her husband made her give up her job when they got married. Aditi was keen to start work again, however, and had just managed to convince her husband that two incomes were necessary if they were to survive with the HIV. She lived with her husband in a one-room-kitchen flat provided by the company he worked for as a bus conductor.

Three months after their marriage in 1997, Aditi developed genito-urinary problems, which led to her discovering that both she and her husband were positive. Aditi believed she contracted the virus through her husband, who said he could have got it from a sex worker. She blamed HIV for robbing her of her newfound happiness and the chance of motherhood. She said that she lived with the hope that the "English medicine" would soon be available to cure her. Aditi was HIV asymptomatic at the time of the interview.

### **Respondent 3**

Namita (B. 3), age 26, lived in Bombay. She dissolved into tears often during the interview. After school, she trained to be a nursery teacher, but never worked, because she got married soon after finishing her training. At the time, she was learning how to type and learning the English language.

Namita received her diagnosis in 1995, after her husband was diagnosed with AIDS. She was widowed in 1998, when her husband succumbed to the disease. She believed she contracted the virus through her husband, who contracted it through a sex worker. She recalled that the time before she was diagnosed, was especially painful because of mistreatment by her in-laws. Just before his death, her husband forced her to leave his home because he knew his family would treat her inhumanely after he died. Namita lived in her father's home with her siblings and their families. Her brother supported her financially. She looked forward to the new 'AIDS cure' that she believed would come to India. Namita was HIV asymptomatic at the time of the interview.

### **Respondent 4**

Parul (B.4), age 20, lived in Bombay. She was cheerful and spoke with a great deal of determination. She had been unable to complete her schooling, because she became engaged to be married when she was 15. She lived with her family in a one-room house in a *chawl*. She said it had always been her dream to study and become someone. Parul had never been employed and her parents supported her financially.

HIV was already a part of Parul's life when she received a positive diagnosis in 1996. Her fiancé had previously been found to have AIDS, to which he succumbed in 1997. She believed she contracted the virus through her fiancé, who contracted it from a sex worker. She recalled the brief happy time she spent with her fiancé, before he was diagnosed and the deep unhappiness that followed when he became critically ill and died. Parul said that if she were cured she was determined to do some good for the world and for other women who suffered similar pain as her. Parul was HIV symptomatic at the time of the interview.

### **Respondent 5**

Prabha (B.5), age 30, lived in Bombay. She seemed restless during the interview and reported feeling very weak. She spoke very softly and slowly. She recalled how much she loved school and was even quite bright at her studies, but was forced to drop out of junior school because her family, who belonged to a very low caste, were very poor and needed her to work. She worked as a domestic for a few years before she was married.

Prabha recalled the pain she experienced being married to a violent, alcoholic husband. Incapable of bearing the pain, she ran away from her husband, only to be tricked by an aunt, who sold her in Bombay as a sex worker. Prabha spoke movingly about the terror, pain and humiliation she had experienced in her life. She lived in a brothel, with her one and a half year old son.

In 1997 when she became pregnant, she discovered she had AIDS. She reported being humiliated by hospital staff, both because she was a sex worker and because she had AIDS. She believes she contracted the virus through her work. Prabha had AIDS at the time of the interview and was very eager to get her child adopted before she died.

### **Respondent 6**

Leela (B.6), age 27, lived in Bombay. She narrated her story with great strength. Orphaned early in life, she was forced to drop out of school before completing her primary education. She recalled that she was very happily married and six months pregnant for the second time when her husband was diagnosed with AIDS. In the three months that followed, her husband's health deteriorated rapidly. He died 10 days after she gave birth to a stillborn baby. When Leela was widowed in 1996, she started working as a domestic to support herself and her remaining son. She lived with her son in a rented one- room accommodation.

Leela believed that she had become infected through her husband, who apparently contracted the disease from a doctor's infected needle. She was the only respondent who received support from an AIDS NGO. Leela was symptomatic at the time of the interview.

### **Respondent 7**

Kumud (B.7), age 35, lived in Bombay. She spoke very slowly and broke into sobs several times during the interview. She completed primary school and went to work with her parents in their shop. In 1989, she married and had 2 children. Four years later, in 1993 when she was 5 months pregnant with twins, the kerosene stove at which she was cooking suddenly burst. Kumud sustained 50% burns on her chest and neck and required a blood transfusion.

In 1997, both she and her husband developed T.B. at roughly the same time and both tested positive. All her children were then tested, and it was discovered that both the twins were positive. The doctors believed that the blood she received at the time of her accident was infected. In the course of the next year, her husband and one of her twin girls developed AIDS. Her husband and child later died within 46 hours of each other. Kumud continued to experience grief over the loss of her daughter and husband on a daily basis. She lived with her three children in a rented one-room accommodation. Her family and community provided her with some financial and other practical support. Kumud had AIDS at the time and was terrified about what would happen to her children when she died.

### **Respondent 8**

Nisha (B.8), age 40, lived in Bombay. She spoke with a great deal of enthusiasm and courage. She never went to school because she was a girl and there was plenty of work to be done in the fields. In 1982, she married a truck driver and recalled having a fairly routine life. They lived with their three children in a one-room house that her husband built in a slum in suburban Bombay.

In 1994, her husband was diagnosed with AIDS related dementia. The next 10 months of their life before he died were very difficult emotionally and financially. After her husband's death she tested positive. She reported feeling ashamed because her children were old enough to understand how their father had been infected. She hoped she would survive until all three children were well settled, and that the "miracle cure from the West" would soon be available. Nisha was HIV symptomatic at the time of the interview.

### **Respondent 9**

Meera (B.9), age 26, lived in Bombay. She spoke very gently and smiled all through the interview, even when her eyes were brimming with tears. She dropped out of junior school because she was physically very weak and had never worked outside the home. In 1990, Meera was married and recalled feeling lucky to be so happy and well loved by her in-laws. In 1994, she was pregnant for the second time when her husband was diagnosed with AIDS and cancer. She believed that he had been infected by a sex worker.

In 1995 both she and her infant son tested positive. Meera said that she felt a great sadness because her innocent child had received such a punishment. They were both HIV asymptomatic at the time at the time of the interview. She lived with her two children and her mother in a one-room house bought by her husband.

### **Respondent 10**

Champa (B.10), age 27, lived in Bombay. She spoke very emphatically throughout the interview. She never went to school because her mother was a poor widow from a very low caste and they had to work as domestics to feed themselves. At 14, she was married to a man 20 years her senior because her mother was dying of tuberculosis. Champa said she never knew happiness in her marriage and that she suffered harsh and inhumane treatment from her in-laws.

When her husband tested positive in 1996, his family blamed her for it and she was thrown out of the house. She recalled feeling lost, because she had no family or friends to turn to. In 1998, she became very ill and discovered that she also has AIDS. At the time of the interview, Champa worked as a domestic and lived at the home of her employer, but was frightened that they would someday find out that she had AIDS and throw her out. She said that her only wish was to have a quick and painless death.

### **Respondent 11**

Urmi (B.11), age 30, lived in Bombay. She spoke very slowly. Throughout the interview she never looked directly at me, and had a distant, fixed gaze. After high school, she did not study further, nor did she ever do a job outside the home. In 1991, her first husband died in a car crash while returning from a pilgrimage, leaving her with a six-month-old daughter.

A year later Urmi remarried a gentle man who loved her baby as his own. She said that they were very happy for the first two years. In 1994 she developed genital boils, and tested positive. Her husband and daughter also tested positive. It was then that she realized that her first husband had infected her. In 1995, her daughter developed AIDS. Urmi recalled how her child had suffered and the strength and courage she had shown. She said that her husband was a living God and that neither he nor his family had ever blamed her for infecting him. Her daughter died six months before the interview. Her husband and she were both HIV asymptomatic at the time of the interview. Urmi lived with her second husband and his parents in a two-bedroom flat owned by them.

### **Respondent 12**

Rashida (B.12), age 22, lived in Bombay. She smiled throughout the interview, and giggled nervously when she broke into tears during the interview. She never went to school or held a job. She was married at 15 to a man almost 30 years her senior.



Widowed four months before the interview, Rashida lived with her two sons and her husband's family in a two-room accommodation owned by them.

Rashida believed she contracted the virus from her husband, whom she believed had visited sex workers before their marriage. He had been unwell throughout their married life and in 1995, a nurse told her about the true nature of his illness. Rashida was 5 months pregnant at the time and tested positive. Fortunately both her children were negative. Her in-laws treated her with great contempt and blamed her for their son's diagnosis.

She said that being positive had not really made a difference to her life, but being treated like an untouchable had been unbearably painful. She said she wished she could live long enough to tell her children the truth about her life, so that they would not grow up to blame their mother. Rashida was HIV asymptomatic at the time of the interview.

### **Respondent 13**

Savita (B.13), age 21, lived in Bombay. She was very angry during the interview and burst into tears. She dropped out of junior school, and had never done any work outside the home. Savita came from a poor, low caste family, where her father was an alcoholic. At sixteen her mother married her to a man 25 years her senior.

During the year she was married; her in-laws treated her very badly, and taunted her about the limited dowry she had brought into the marriage. Savita recounted that her sole *raison d'être* was to care for her sickly husband, because she loved him and hoped he would get well. At the time, she was unaware that he had AIDS. He died on their first wedding anniversary, when she was just seventeen. Just before he died, he asked for her forgiveness and explained that people told him he would be cured if he married a virgin. Savita recalled that she could not understand what he meant at the time, and cried and mourned his loss. Since then, Savita returned to live with her parents and brother in a one-room house they rent in a slum.

It was only in 1997 that she discovered that she had HIV. Savita said that her life was on hold until the “English medicine” that cured HIV would be available in Bombay. She was HIV asymptomatic at the time of the interview.

#### **Respondent 14**

Priya (B.14), age 27, lived in Bombay. She cried several times during the interview. She never attended school or worked outside the home. She was married in 1992 and moved in with her husband’s parents. Priya recalled that she suffered from the day she entered that house on account of the dowry she had brought.

In 1995, when her husband became very ill and was diagnosed positive, her mother-in-law accused her of being unfaithful to him and causing the illness. A year later, when he died, she and her two daughters were thrown out of the house. Priya went back to live in her parents’ one-room rented accommodation in a slum. Six months before the interview, she tested positive after she developed pneumonia. She was very grateful to God for sparing her children from HIV. She was HIV asymptomatic at the time of the interview.

#### **Respondent 15**

Lakshmi (B.15), age 33, lived in Bombay. She spoke very slowly. She never went to school because her family, who belonged to a very low caste, could not afford it; nor had she ever worked outside the home. In 1982, when she was sixteen, she was married to a man 20 years her senior. She spoke with great pain about the physical and emotional suffering she experienced during the 14 years she spent in her husband’s home.

Lakshmi believed she contracted the virus from her husband, who almost certainly had visited sex workers before and after they were married. He was diagnosed with AIDS in 1993, but did not tell her about his diagnosis. She learned about it a few months later during a fight, when her mother-in-law accused her of being unfaithful and giving her son a deadly illness. Despite the problems, she took care of him for

three years, until his death in 1996. A week after her husband died, she and her daughters were asked to leave the house. Lakshmi and her two daughters went to live with her mother in a rented one-room accommodation in a *chawl*.

In 1998 she became ill and tested positive. She said that, after everything she had gone through in her life, having HIV seemed quite insignificant, and did not really affect her at all, as long as she could be alive and look after her children until they were married. Lakshmi had symptomatic HIV at the time of the interview.

## Positive Women from Edinburgh

### Respondent 16

Julia (E. 16), age 37, lived in Edinburgh. She conveyed a sense of resoluteness and sadness balanced with humour. She said she considered herself to be “a feminist and quite politicised”. She held a BA (Honours) degree in Communications and had worked towards a PhD, which she did not complete for personal reasons. Julia recalled having done a variety of interesting developmental jobs and was very keen on working in the Third World. She was divorced and lived by herself in a private, rented flat.

Julia said that her life before she was diagnosed was rather intense, and her persistent health problems had led to her being tested. When interviewed, Julia had known her HIV status for less than three months, and was unsure whether she contracted HIV from her last relationship or from an earlier relationship. Julia was HIV asymptomatic at the time, and was uncertain whether she wanted to try combination therapy.

### Respondent 17

Jasmine (E. 17), age 37, lived in a town outside Edinburgh. She said that participating in an interview about her life was too painful. Instead, she answered some questions, but found it easier to write out the most difficult parts. She had

taken a course on Caring and Social Care, but was doing volunteer work at the time of the interview. She was divorced and lived with one of her two sons in a home she owned.

Jasmine was raped when she was 22, and was only just coming to terms with the resulting trauma when she tested positive for HIV. She was unsure whether she contracted HIV from a boyfriend or from the rape. In 1986, HIV was highly stigmatised, and as a result, her mother petitioned the courts and received the custody of Jasmine's two-year old son. Jasmine recalled that her life fell apart at that stage. Over the years, she had worked on herself and slowly overcome many of her problems. Jasmine had been HIV asymptomatic for 15 years at the time of the interview but was planning to undergo combination therapy.

### **Respondent 18**

Andrea (E. 18), age 44, lived in Edinburgh. She had a sense of humour and told her story very methodically, because she had told it many times before. She left school at 15 and went to work in a factory. At 17, she got involved in drugs and sex work. She recalled that her life before she was diagnosed had been chaotic and violent, because she dealt in drugs and sold sex to support her heroin habit. She highlighted the plight of women, such as herself, who suffered at the hands of the police, doctors, drug dealers, and clients.

In 1984, she was among one of the first women in Edinburgh to be diagnosed with HIV, although she was unsure whether she contracted the virus through sex work or through injecting drug use. She asserted that she was one of the first women to be put on the methadone programme in Edinburgh, which helped her out of heroin and sex work. In 1992, she got off methadone and has enjoyed a better quality of life. She lived alone in a supported accommodation owned by the Council, and participated in many activities for positive women. At the time of the interview, Andrea was HIV symptomatic and unsure about the efficacy of the combination therapy that she had been on for the past year.

### **Respondent 19**

Susan (E. 19), age 38, lived in Edinburgh. She was very soft-spoken. After school she worked in several small jobs, but had stopped working after the birth of her son. She lived with her second husband and son in a home that they were renting from a Housing Association.

In 1985 she was diagnosed positive, but asserted that she never thought of herself as being positive and had never been ill for even a day in her life because of HIV. Her life before she was diagnosed had been troubled. She had just given birth to a child, and her husband, an injecting drug user, was dying in prison. Her mother had just died and her father needed special care. She recalled that her life was so rushed and full of other worries that she had pushed HIV out of her mind.

Susan was HIV asymptomatic at the time of the interview, with viral loads that were undetectable at the time and had never considered combination therapy.

### **Respondent 20**

Wilma (E. 20), age 42, lived alone in a flat she rented from the Council in Edinburgh. She was deeply disturbed and cried loudly at times throughout the interview, which took place over a period of six hours.

After completing school, she worked as a trainee seamstress in a theatre and as a laboratory technician, and loved both the jobs. Wilma's first marriage broke down when she was 20; her second husband tried to slit her throat and almost killed her, and her third husband battered her badly. Within a few short years, she was raped, dabbled in drugs, lost her job, and eventually ended up working in a sauna, where she was forced into prostitution to buy drugs. She described the extreme violence and abuse she experienced as a result of her lifestyle of heroin addiction and sex work. She believed that heroin addiction and everything associated with it were synonymous with hell.

In 1986, while in prison, she was told that she had HIV, cervical cancer, and sexually transmitted diseases, and only two years to live. After she left prison, she got off drugs and out of sex work and managed to get some order back into her life. Wilma had symptomatic HIV at the time of the interview, but was unsure whether it was injecting drug use or sex work that infected her. She was on combination therapy, but did not know whether it really helped her.

### **Respondent 21**

Molly (E. 21), age 36, lived in Edinburgh. She spoke with a great deal of enthusiasm and energy. She was widowed and lived with her daughter in a flat they rented from the Council. She did not have any formal training after school. She worked as a volunteer in her spare time, with a self-help group for positive people.

Molly recalled that the depression that she experienced because her husband was in prison and she was alone with a new born baby inadvertently led her to heroin use. In the mid- 1980s, soon after she was diagnosed, she lost her husband, brother, and sister-in-law to AIDS. The pain and loss she experienced, together with the support of her family and the responsibility of caring for a young child, helped her to get off heroin. Molly was HIV asymptomatic, on combination therapy, with a viral load that was undetectable at the time.

### **Respondent 22**

Belinda (E. 22), age 26, lived in Edinburgh with her daughter and partner, in a flat they rented from the Council. She spoke with great confidence. She did not have any formal training after school, and was working in a supermarket at the time of the interview. She hoped to pursue a career in counselling.

Before her diagnosis, she recalled having a 'normal' and happy life. In 1990, at the age of sixteen, her life suddenly changed when she tested positive, after her boyfriend told her about his positive diagnosis. She said that knowing she was positive made it very difficult for her to cope and make sense of her life, which led her into heavy drug abuse. The chaos and pain that she experienced eventually led to



the decision to make the best use of the time she had left, and she reordered her life. Belinda had been HIV asymptomatic for 10 years when interviewed, and had never taken combination therapy.

### **Respondent 23**

Allison (E. 23), age 35, lived in Edinburgh with her two daughters, in a flat she rented from the Council. She spoke with great enthusiasm. She reported that she had always dreamed of being a social worker, and she had even started training for it, but found the real life situations of other people too painful to handle.

She recalled that it had been fashionable to take drugs in the early 1980s, and she enjoyed injecting heroin. She highlighted how her habit caused her to participate in anti-social and sometimes criminal behaviour. However, when she met her partner and became pregnant, she gave up drugs completely because she was very keen on being a good mother.

In 1986, she discovered she was HIV positive. She recalled the inhumane treatment she received from medical professionals because she was positive and had been a “junky”. She was unsure how she had been infected. At the time of the interview, Allison was HIV symptomatic and on combination therapy, but did not know whether it really helped her.

### **Respondent 24**

Cynthia (E.24), age 43, lived in Edinburgh with two of her three children in a flat they rented from the Council. She reported feeling weak and spoke haltingly and softly. She had dropped out of school and had never been employed.

Cynthia had suffered many years of extreme domestic abuse from her husband, who was an injecting drug user. For a short while she too had injected drugs. In 1984, she was diagnosed positive, and believed that her husband had infected her.

Her account described the many adversities she had experienced both before and after diagnosis: the death of a baby sibling, acute domestic abuse, and the methadone addiction of her nineteen-year-old daughter (herself a mother of four) that led to her grandchildren being placed under the supervision of the social services.

Cynthia's account highlighted the constructive support she received from organizations for positive women and the buddy service in Edinburgh. Cynthia was HIV symptomatic at the time, and reported that combination therapy had created a lot of physical problems for her.

### **Respondent 25**

Janetta (E. 25), age 26, a college graduate, lived in Edinburgh. She found it difficult to answer some of the interview questions, and often cried and bit her lip. She lived in her parents' home with family who were supportive to her. After graduation, she had worked at many small jobs, but was unemployed at the time of the interview.

Tiny irritating health problems had led to her diagnosis, which had come as a complete shock to her. This occurred 18 months before the interview. Her account highlighted the pain, emotional turmoil, and bitterness she experienced because of the unexplained disappearance of her boyfriend.

Janetta was HIV asymptomatic at the time of the interview, and had never considered combination therapy.

### **Respondent 26**

Marcia (E. 26), age 39, lived in Edinburgh with her two teenage girls, in a flat she rented from the Council. She smiled and joked at times during the interview. She was unemployed and emphasized that her life "revolved and rotated" around her children.

In 1985, she was diagnosed positive when she went into hospital for a minor procedure. Her life at the time was not easy: her husband had recently died while

serving a prison sentence because of drugs; her younger child had been diagnosed a slow learner and required special attention; and her only support, a caring brother, was meaninglessly murdered.

Marcia was HIV symptomatic at the time of the interview. She was unsure whether she wanted to start on combination therapy, as advised by her doctor, because of all the conflicting stories she had heard about it.

### **Respondent 27**

Shirley (E. 27), age 30, lived in Edinburgh with her boyfriend and five year-old child, in a flat she rented from the Council. She spoke softly, yet resolutely. She grew up with loving foster parents because her biological father was violent toward her and her mother. Shirley never went to college, although she would have liked to. She had been unemployed since she became pregnant, but had held several small jobs in the past.

In 1985, Shirley had been in a long-term relationship with her boyfriend when, she discovered she was pregnant and positive. She recalled being heartbroken at the thought that they could have infected their child. Both she and her partner were HIV asymptomatic at the time of the interview and were greatly relieved that their child was negative.

## **Patterns Emerging from Women's Biographical Information**

The patterns distilled from the respondent's biographical information corresponded closely to relatively established "ground realities", that is, the patterns of existing demographic and social characteristics associated with HIV infection. Through their uniqueness and commonalities these patterns reflected the personal context of the respondents.

## **Age**

There was a considerable variation between the age of the respondents in Bombay and that of those in Edinburgh at the time of the interview. It is possible that this age difference among the respondents at the point of being interviewed may have influenced the findings. Respondents from Bombay ranged between the ages of 20 and 40, with a mean age of 28 years. The ages of the Edinburgh respondents ranged between 26 and 44, with a mean age of 36. Thus the Edinburgh respondents were considerably older when interviewed.

The age at which respondents had first discovered they were positive mirrored prevalent trends in society. The majority of respondents from both cities discovered they were positive in their mid-twenties. The age when the respondents in Bombay were diagnosed HIV positive ranged between 17 and 35, with a mean age of 25. For those in Edinburgh, the age of diagnosis ranged between 16 and 36, with a mean age of 25. It can be seen that the mean age of discovery in both settings was the same.

The literature asserts that the age group when people are most likely to be infected is during their most economically productive and reproductive years. On a global scale, 50% of women newly infected with HIV/AIDS are between the ages of 15 and 24 (ICW 1998). In the most-affected countries, HIV/AIDS is spreading fastest among young people below the age of 24 (UNFPA 2001a). Ninety percent (90%) of the total reported HIV/AIDS cases in India occur in the sexually active and economically productive 15 to 44 age group (UNGASS 2001). In the UK, the majority (85%) of HIV infections and 80% of AIDS cases were found to be in the 20 to 39 age group (PHLS AIDS Centre and SCIEH 2001). In 1985, during the peak of the HIV epidemic in Edinburgh, the mean age for new infection among injecting drug users was approximately 25 years of age (Brettell 1995).

## **Education**

A significant number of respondents from Bombay reported that they never attended school or were compelled to drop out of primary school because they were needed to

work at home, in the fields, or at a job in order to support their families. Poverty and belonging to a low ranking caste were mentioned as the reasons for prematurely ending their education. According to NCERT (1995), girls in India suffer from an abnormally high incidence of school dropout. Many are “pull-outs,” withdrawn from the educational system by the sheer force of socio-economic and cultural compulsions. By comparison, all the women in Edinburgh (with the exception of one) reported completing their schooling, and did not mention any social or financial impediment to the process. In general, women in Edinburgh had a higher level of education, which in turn, could have an influence on their experiences of living with HIV/AIDS.

## **Employment**

The level of employment was low among respondents in both Bombay and Edinburgh. A majority of respondents were unemployed and had never been employed before. Women who had been employed earlier stopped working when they became pregnant or gave birth. None of the respondents reported becoming unemployed on account of their being positive; however, a woman in Bombay did express fear that she might be thrown out of her job as domestic worker if her employer discovered her AIDS status. A few women in Edinburgh were involved in volunteer work, largely with other positive persons.

## **Accommodation**

The majority of respondents in Bombay lived in socio-economically deprived areas of the city, in rented, one-room accommodations, either in slums or *chawls*. Women in Edinburgh rented accommodations from the City Council, with the exception of two women, one who rented through a Housing Association and the other through a private landlord accommodation. Some women who lived in council estates before they were diagnosed alluded to the deprivation in the areas where they lived. McRae (1989) points out that poverty and deprivation were widespread in many of the council estates on the periphery of Edinburgh.

## **Year of Infection**

Whereas the majority of women in Bombay reported being infected in the mid-nineties, the majority of the women in Edinburgh reported being infected in the mid-eighties. This trend among respondents mirrors the trend of the society to which they belong. In India, HIV transmission to monogamous wives was acute in the mid-nineties (Quinn 1996) whereas, in Edinburgh an epidemic of HIV (clinically unrecognised at the time) began abruptly in 1983 (Brett 1995).

## **Mode of Transmission**

The majority of respondents in both Bombay and Edinburgh reported being infected heterosexually by their husbands or partners. UN Population Fund (2000) found that more than 70 percent of HIV infections worldwide occur via heterosexual sex. In India, HIV appears to have moved into the homes of Indians in low-risk groups in the general population (Mane and Maitra 1992, Pais 1996), and has spread among young, monogamous, married women who become infected by their husbands (Gangakhedkar et al. 1997). Married men who visit sex workers are believed to be the primary group responsible for the rapid spread of the disease.

Additionally, HIV has also spread rapidly in the red-light district of Bombay and along the truck route to and from the city (Gerster 2000). After becoming infected with the virus, many times truck drivers unknowingly infected their wives and through them, their future children (McDonald 1992, Narain et al. 1994).

A few women who were infected in the mid-eighties in Edinburgh reported that they were unsure of how they were infected, whether heterosexually, through involvement in sex work, or through injecting drug use. This is because the appearance of HIV in Edinburgh coincided with the epidemic of injecting drug use that was at its peak in the early 1980s (Robertson and Bucknall 1986, Robertson et al. 1986).



## **Progression of HIV**

The majority of respondents in Bombay (8,  $n_1 = 15$ ) and Edinburgh (7,  $n_2 = 12$ ) reported being HIV asymptomatic. Four respondents from Bombay and five respondents from Edinburgh reported having symptomatic HIV. Three respondents from Bombay reported having AIDS, while none of the respondents from Edinburgh reported having AIDS. Access to medical health facilities and treatment, along with a higher nutritional status, are important factors in preventing HIV from converting to AIDS. Brett (1995) points out that the epidemic in Edinburgh was detected within two years of its onset, when the majority of infected individuals were asymptomatic and as a consequence, there was the opportunity to develop specific services for HIV before the onset of HIV-related illnesses or AIDS.

## **Conclusion**

This chapter introduced the respondents and provided a brief summary of their life circumstances. It threw light on the patterns that emerged from their biographical details, allowing me to look at their accounts in relation to the previously existing data on HIV/AIDS. It also offered me an insight into the lives of the respondents, as individual women living with HIV/AIDS, as well as, collectively, as positive women.

The next three chapters are the findings chapters. Chapter 5 is devoted to the Pre-Diagnosis stage, Chapter 6 is devoted to the Diagnosis stage, and Chapter 7 is devoted to the Post-Diagnosis stage.

## CHAPTER 5: THE PRE-DIAGNOSIS STAGE

### Introduction

This chapter aims to extend and deepen the understanding of the respondents' experiences during the pre-diagnosis stage. The women were asked to describe their lives before they were tested and received a positive diagnosis. The questions asked were aimed to take the respondents to the beginning of their story of living with HIV/AIDS. They were encouraged to share their memories, feelings and emotions about the pre-diagnosis period against the time frame of the year in which the diagnosis was made.

As mentioned in Chapter 2, the key issue for this stage is that of vulnerability. This issue focuses on the personal characteristics and life experiences and that put these women at risk for HIV/AIDS. Based on the information that I obtained from the women, I developed the assertion that the participants in my study were vulnerable at all three of the levels described previously: individual, social, and structural.

### Vulnerability to HIV/AIDS

An awareness of the vulnerability experienced by positive women, provides a basis to understand the phenomenon of women living with HIV/AIDS. The word 'vulnerable' is derived from the Latin word *vulneris* or 'able to be wounded or hurt' (Moutoux 2001). The vulnerability of women in Bombay and Edinburgh emerged from a complex interaction of individual, social and structural issues.

This section portrays a striking picture of the socially and culturally induced vulnerability to HIV/AIDS: women who at the end of the second decade of the epidemic have never heard about HIV/AIDS; women who did not know anything about disease transmission or about protecting themselves against it; women for whom the immediate life concerns like food, clothing, shelter, and health care, or

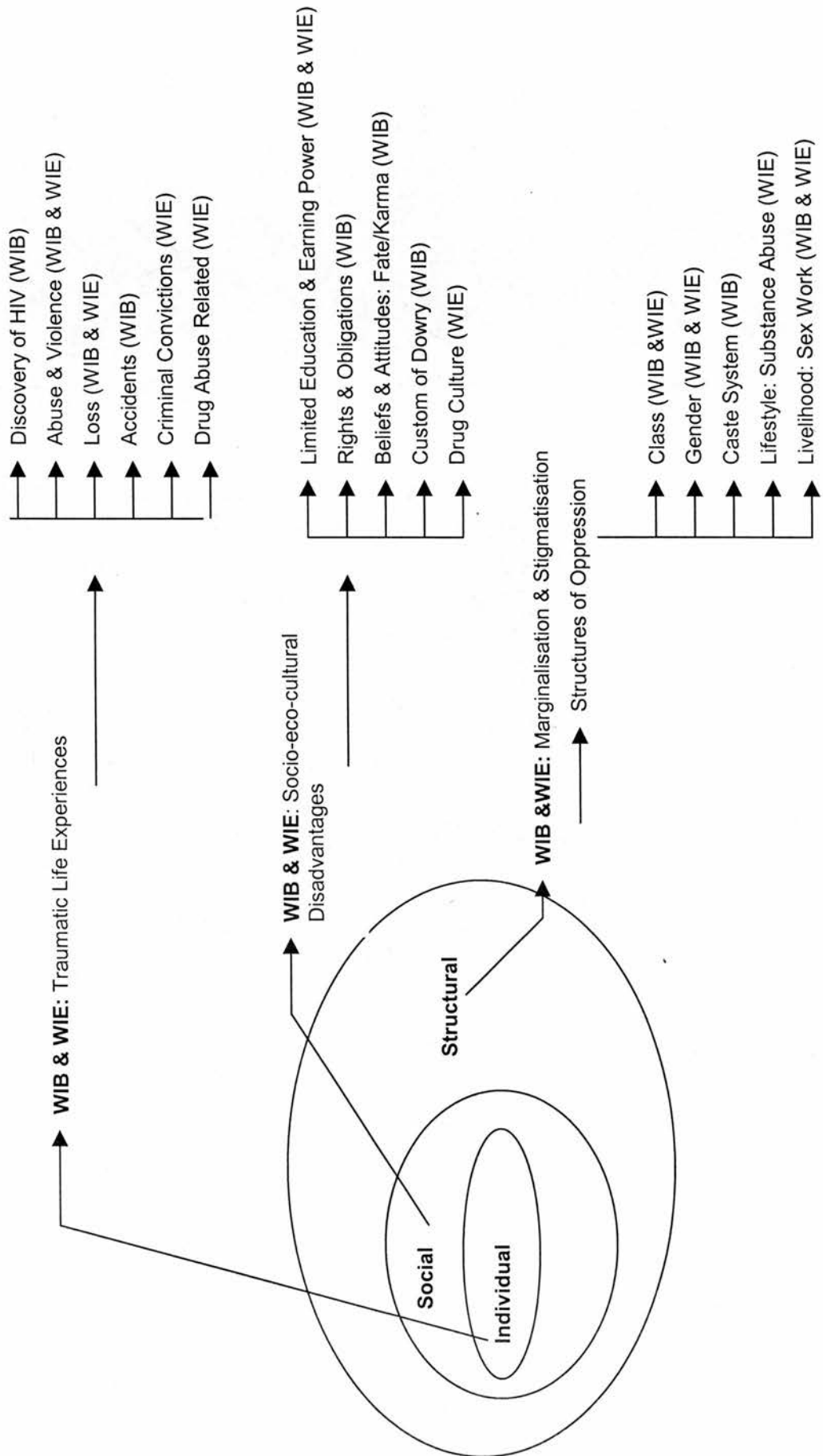
drug-induced physiological and psychological problems were so profound that long-term concerns like HIV/AIDS were irrelevant.

In exploring the data that emanated from the women's accounts in the pre-diagnosis stage, it became clear that a significant number of women from both Bombay and Edinburgh had lived through some kind of traumatic stress experience that made them psychologically vulnerable to contracting HIV. The nature of the traumatic stresses experienced by the women and the ways that these traumatic stresses increased the women's vulnerability will be explored.

The accounts of the women also revealed the varied aspects of socio-economic and cultural disadvantages that created vulnerability at a social level. These disadvantages include lack of education, poverty, fatalistic beliefs about faith and karma, and various social rights and obligations that led to the women's social vulnerability.

The third level of vulnerability for these women is structural in nature. Marginalization and stigmatisation experienced by women during the pre-diagnosis stage reflected the structures of oppression (Jackson 1999): class, caste, gender, and a lifestyle that included substance abuse and or sex work—all of which rendered them vulnerable. The oppressive structures of gender, class, and a lifestyle that included sex work were issues commonly experienced by women in Bombay and Edinburgh. In contrast the issue of caste was specific to Bombay and the issue of drug use was specific to the women of Edinburgh.

Figure 5.1 illustrates the issues associated with vulnerability for the women in Bombay and Edinburgh.



**Figure 5.1:** An illustration of the Multiple Sources of Vulnerability of the Women in Bombay and Edinburgh during the Pre-diagnosis Stage. **WIB** = Women in Bombay **WIE** = Women in Edinburgh.

## **Individual Vulnerability**

Individual vulnerability is based on personal characteristics that increase a woman's risk for contracting HIV. It encompasses both physiological and psychological characteristics. Physiological vulnerability includes the characteristics of the female body that render all women vulnerable to HIV infection. These will not be discussed in detail here, since they are not specific to the women in my study. This section will concentrate on factors that increase the psychological vulnerability to infection. These include a variety of personality characteristics and abilities, as well as life experiences that impact a woman's self-protective behaviour.

For the women in my study, the common theme underlying their individual psychological vulnerability to HIV/AIDS was that of trauma, and particularly that brought about by violence. Nearly all of my participants had experienced some sort of traumatic experience in the time period prior to their infection, and for many of the women, the trauma took the form of violence. These issues will be explored more formally in the next sections.

**Traumatic Life Experiences.** To explain the issue of individual vulnerability, I have drawn from the literature on traumatic stress experiences. I did so because the majority of women from both Bombay (15, n=15) and Edinburgh (10, n=12) recalled experiencing traumatic life experiences during the pre-diagnosis stage. Trauma comes in many forms, and there are vast differences among people who experience trauma. But the similarities and patterns of response cut across the variety of stressors and those who experience it (Giller 1995). Many of the traumatic experiences could be described as single blow traumas. Terr (1991) suggests that single blow traumas are experienced in the case of natural disasters (such as earthquakes, hurricanes, fire, floods, and volcanoes) or technological disasters (such as auto and plane crashes, chemical, and nuclear spills) or criminal violence (such as robbery, rape, and homicide) which, she suggests, not only have a great impact on the victims, but also on witnesses or loved ones of victims.

**Natural disaster:** Kumud (B.7) experienced a natural disaster when the kerosene stove at which she was cooking burst. She sustained 50% burns, on her chest and neck area. She was five months pregnant with twins at the time. When she recalled the experience, she said she could only remember the intense shock and pain.

**Technological disaster:** Urmi's (B.11) account described a single blow, technological disaster, when she was involved in a car crash while returning from a pilgrimage that killed her first husband. She recollected her feelings of helplessness and finality at being widowed at 20 with a 6-month-old baby.

**HIV/AIDS related Trauma:** The diagnosis of HIV/AIDS in a loved one can also be a traumatic life event. Women in Bombay reported this event as a very painful, shocking period in their lives prior to their own diagnosis. Among the emotions reported by the eleven women in Bombay who had HIV in their lives prior to their own diagnosis were fear, anxiety, sadness, and grief associated with having a foreshortened future. It is interesting to note that not one of the eleven women said that they had any fears of being infected when questioned about it.

Kaplan and Saddock (1985) point out that reactions to traumatic events vary considerably, ranging from relatively mild, creating minor disruptions in the person's life, as reflected in the recollections of Urmi (B.11) and Susan (E.19), to severe and debilitating as reflected in the recollections of Jasmine (E.17).

Urmi (B.11) reported that she accepted her husband's death as something that could not be changed. She said:

***"You want to cry, but you don't. If you keep crying it does not help ...you have to bear what you cannot change ... you just have to go on ... means that you have to go on."***

Susan (E.19) expressed similar feelings. She recalled that in spite of the loss of her mother, and her father being seriously ill, and all the hurt she was experiencing, she continued to carry out her normal day-to-day responsibilities without breaking down. However Jasmine (E.17) recalled the pain as intense and debilitating. She said:



***“I was out of my mind. I felt I had lost everything. I just existed. I don’t know ... it was all a haze. Looking back I can only remember pain”.***

Kaplan and Saddock further suggest that it is very common for people to experience anxiety, fear, shock, and upset, as well as emotional numbness and personal or social disconnection.

Although the literature on PTSD does provide a lens through which to view the effect of traumatic stress experiences on women, the experiences reported by the respondents in this study are not, *per se*, to be interpreted as manifestations of it because PTSD is a complex syndrome that requires a psychological evaluation in order to be diagnosed. At no point in any of the interviews related to this research did the respondents or the researcher ever mention PTSD diagnosis or testing. Thus, the accounts of the women are viewed only as revealing the traumatic life events that contributed to their vulnerability at the individual level.

**The Trauma of Violence.** A significant number of respondent accounts revealed that they experienced physical, emotional, and mental abuse and violence in their lives. Male violence against women is a worldwide phenomenon (Coonrod 1998) and domestic violence, rape, and sexual abuse are widespread across all regions, classes, and age groups. UNAIDS (2000) points out that noticeably, in situations where violence is regarded as a man’s right, women are in a poor position in their relationship, which compromises their ability to protect themselves. Violence directed against women makes them vulnerable to HIV infection in both direct and indirect ways (UNAIDS 2000). The relationship between violence and HIV is often indirect, where the fear of violence makes it more difficult for women to refuse unsafe sex. In addition, violence against women, such as trafficking, forced prostitution, incest and rape - including marital rape - all put women at a direct risk of contracting HIV and fuel the HIV/AIDS epidemic (Population Reports, 1999). Sexual violence is more direct, and the incidence of HIV/AIDS transmission in the context of coerced sexual intercourse is exceptionally high (UNAIDS 2000). Thus, violence against women is a significant contributor to the spread of HIV/AIDS (Gordon and Crehan 1999; Brundtland 2000; UNFPA-OBP 2000).

In Bombay the partners and in-laws of the women tended to be the perpetrators of abuse; whereas, in Edinburgh, the perpetrators included partners, clients in sex work, rapists, drug dealers, and the police. The literature suggests that women are most at risk at home, because often the abuser is a member of their own family. Mothers-in-law may abuse in-marriage women (Gordon and Crehan 1999) or men whom they know may be the abusers (UNFPA 2001b). Jejeebhoy (1998) suggests that, in developing countries, a third or even half the women are beaten by their partners. Although violence against women is routinely under-reported, studies in developing countries consistently find high levels of domestic abuse, rape, and other kinds of violence among women with HIV/AIDS (Coker et al. 1998).

Another particularly serious form of violence is related to sex work. Respondents' accounts highlighted the plight of women in sex work and the nexus with drug use and violence. McKeganey and Barnard (1996) note that prostitution is an act of 'ever present' violence against women. The account of one woman in Bombay described how an abusive, alcoholic husband forced her to flee his home and made her a target for trafficking. Broken marriages can also leave women marginalized with few options for other incomes (Larson and Narain 2001). The economic needs of women in developing countries drive them into sex work, which ultimately fuels the HIV epidemic. Once women have become engaged in sex work, they are subject to further violence related to their illegal status. The narrations of two women in Edinburgh and one woman in Bombay, who worked in sex work, all reflect violence, abuse, and ill treatment they received from doctors and the police. Despite their special health needs, sex workers do not receive adequate treatment because of poverty and stigmatisation (Evans et al. 1997; Bharat et al. 2001).

The accounts of some women in Bombay also reflect the emotional violence they experienced. Despite the truth of the manner in which HIV infection entered their lives (de Bruyn et al. 1995), these women were accused of infecting their husbands with HIV/AIDS and were subsequently thrown out of their homes on that pretext. Many women accused of infecting their husbands, have lost the roof over their heads

when their husbands died (de Bruyn et al. 1995; Foreman 2000; Bharat et al. 2001; Sleaf 2001).

## **Social Vulnerability**

The accounts of most of the women revealed that they were disadvantaged socially, economically, and culturally during the pre-diagnosis stage. Factors such as poverty, low levels of education, lack of social support, drug culture, social practices and customs such as that of dowry, disempowering ideas regarding rights and obligations, and fatalistic attitudes and beliefs disadvantaged them and converged to make them socially vulnerable. Cultural myths about sex, for instance the belief that having sex with a virgin is a cure for AIDS, as discussed in previous chapters, added to their vulnerability. A woman's low status because of lack of education, information and services in health, income, and social rights make her socially vulnerable (Petros-Barvazain and Marson, 1990). Also, poverty breeds powerlessness and lowers the economic and social status of women, which in turn increases their vulnerability (Panos Dossier, 1992).

**Poverty.** The accounts of women in Bombay and Edinburgh revealed their experiences of poverty. A significant number of the respondents in Bombay lived in absolute poverty, that is, they belonged to some of the most deprived sections of Indian society, who lacked the basics of food, clothing, and shelter to subsist (Beresford 1999). The accounts of a few respondents in Edinburgh reflected their experiences of relative poverty during the pre-diagnosis stage, created by lifestyles that included drug use and sex work, or marriage to men who were involved in drug use and other criminal activities. Their experience of poverty was 'relative' because they lacked the resources, amenities, and living conditions that were customary to the society they belonged to (Townsend 1979) and considered as essentials (Mack and Lansley 1985). Relative poverty is based on the wider socio-cultural needs and standards of living of individuals who are provided the basics by the welfare state. However, the poverty of the women in both contexts was highlighted by common indicators such as low literacy rate, a significant gender gap in primary education,

high prevalence of a number of forms of violence against women, and lack of access to financial resources and opportunities for healthy and productive lives.

HIV/AIDS is often referred to as a disease of poverty (Ankrah 1991, Schoepf 1991, Farmer et al. 1996, Connors and McGrath 1997, World Bank 1997, Collins and Rau 2000, IFAD 2001), although it affects people from all classes. The accounts of the women reflect the reality that poor women are disproportionately affected in both developed and developing countries (Berer 1993). The accounts of the women in Bombay also illustrate the fact that the impact of HIV/AIDS on women in a developing world is particularly devastating (Moerkerk 1992).

Rao Gupta (2002) asserts that the majority of the world's poor are women, and most of the world's women are poor. Poverty has a woman's face: of the 1.3 billion people living in poverty, 70 percent are women (UNDP 1999). The HIV/AIDS epidemic hits hardest among the world's poor (Bianco 1995; de Bruyn et al. 1995). Poverty is a gendered experience, and there exists a 'feminisation of poverty'. That is, not only do women experience poverty more often in comparison to men, but the way they experience it also differs (Jackson 1996; Ruspini 2001).

Poverty is a major variable in the transmission of HIV/AIDS. The Panos Dossier (1992) argues that:

***“ With certain exceptions, the overriding reason for the rapid spread of HIV has been the high correlation that exists between poverty and vulnerability to the virus, a correlation that has led to high rates of infection in the most economically deprived populations of cities as far apart as Bombay, Edinburgh, New York and Rio de Janeiro” (p.10).***

Poverty can also accelerate the onset of AIDS and tends to increase the impact of the epidemic (Collins and Rau 2000) by impoverishing people in such a manner as to intensify the epidemic itself. HIV/AIDS deepens the poverty of already poor individuals. For example, the lives of one woman in Bombay and her family were greatly compromised by the debt they incurred on account of expensive healthcare and funeral expenses, in addition to the loss of her husband, a truck driver who was the only breadwinner. She was forced to withdraw her young teenage children from

regular school so that they could work during the day and study at night. HIV/AIDS further drives the extremely poor into destitution (Collins and Rau 2000). In this study, a Bombay woman who was thrown out of her husband's home as soon as it was discovered that he had AIDS was left on the streets penniless and destitute. Terrified of the consequences of her destitution, she managed to obtain a job as a domestic worker. However, she lived with the fear that she would become a destitute once again, if it were discovered that she had AIDS. Thus, HIV perpetuates the poverty of individuals, families, and societies (Brundtland 2002).

There is no simple association between any one factor of poverty and the risk of HIV infection. There is, however, a link between people's lack of access to resources and economic strategies adopted to survive (Lindenbaum 1992). The accounts of some women in Edinburgh revealed how poverty, induced by drug use, forced them into sex work and criminal activities that ranged from petty thieving to the sale of heroin.

Thus, while not a direct cause of the disease, poverty can create an environment that fosters the spread of AIDS. Often poverty and limited opportunity may function to maintain women in geographically vulnerable communities or areas with high HIV seroprevalence (Berer 1993; Cohan and Atwood 1994), as is reflected in the life situation of sex workers. Moreover, the poverty experienced by the respondents in both contexts placed them in dependent positions that deprived them of the information and control over their lives necessary to protect themselves.

**Limited Education.** The majority of women from Bombay and one woman from Edinburgh did not complete school. The low levels of education among the women in Bombay appeared to affect their earning power negatively. A few women recalled how the only jobs available to them were domestic work that was labour intensive but poorly paid. Savita (B.13) recounted that during the pre-diagnosis stage, after she was widowed, she had been keen to take on a job, but her primary school education only gave her the option of domestic work. She said:

*"I was only fit to scrub dishes, at least if I could read and write properly I could have done some office job. My brother was not going to send me to work in somebody's house."*



Education enhances employment opportunities and provides access to information and awareness. Conversely, illiteracy leads to lack of information, lowered status, and a limited access to economic opportunities and autonomy. Limited education coupled with low earning power and poverty appeared to increase women's economic dependence on men. Wilton (1997) argues that women's economic dependency is expressed in prostitution, a dependency that often reflects and contributes to their subordination by men.

**Lack of Social Support.** The accounts of the women reveal that the majority of them had limited social networks. Social Networks can be conceptualised as patterns or webs of social relationships that are crucial in providing support to individuals. How a person lives is largely dependent on how that person is tied into the larger web of social connections (Freeman 2002). Mitchell (1969) defines a social network as "a specific set of linkages among a defined set of persons" (p.2). Social networks enable an understanding of the linkages existing between different institutional spheres and between different social groups (Srinivas and Beteille 1964).

The majority of the women in both Bombay and Edinburgh reported having strong ties with their families of origin, with mothers and siblings in particular. However, there were some exceptions in both contexts. One woman in Bombay was orphaned soon after she was married at the age of fourteen and was destitute. Another woman in Bombay reported the close emotional ties that existed with her husband's family in the pre-diagnosis stage. One woman in Edinburgh had severed all ties with her biological father because he had abused her and her mother.

Women in Bombay had very limited social support networks other than their immediate family. Some women reported receiving support from their extended family, cousins, and their families. One woman from Bombay spoke about the "great importance" of the support she received from a Women's group that was run by a HIV/AIDS NGO (non-governmental organisation) and how it had helped her to get her life together. She also stressed the importance of meeting and sharing day-to-day problems and issues with other positive women to dispel isolation. On the other



hand, the majority of the respondents in Edinburgh acknowledged the tremendous value of the support they received from HIV/AIDS NGO's. These women echoed the feelings of the woman in Bombay. Additionally they touched upon the therapeutic value of counselling and the Buddy Service.

The accounts of some women revealed the negative consequences of belonging to particular social networks that were already marginalized, and, where the prevalence of contracting HIV/AIDS was greater. The majority of the women in Bombay and some women in Edinburgh belonged to disadvantaged groups, and this situation reduced their capacity to protect themselves sexually. Moreover, Bombay women who belonged to low castes seemed to experience enhanced domestic abuse in relation to dowry. Likewise, some women in Edinburgh belonged to social networks, such as drug users or sex workers, where women engaged in activities associated with a higher prevalence of HIV/AIDS.

**Social Customs and Beliefs.** Two aspects of Indian society combined to increase the social vulnerability of some of the women in my study. One is the caste system, which results in a lowered status for some individuals by virtue of their birth into a lower caste. Women from the lower castes experience discrimination and abuse that reduces their economic and educational opportunities and increases their vulnerability to HIV. Another aspect of India relevant here is the custom of dowry. Disputes over dowry often lead to mistreatment of women and subsequent pressures that increase the vulnerability to HIV.

The accounts of three women in Bombay revealed the abuse they experienced because their in-laws expected a larger dowry, and were persistent in their demands for more. Savita's (B.13) mother-in-law reminded her at least once a day that she had not brought enough dowry and that it was difficult maintaining her on the paltry sum she had brought. Priya (B.15) recalled the constant taunts and demands for more dowry from her mother-in-law. She said that she felt miserable to go home to visit her parents, because that would start a renewed tirade from her mother-in-law.

Another cultural factor that is directly related to the spread of HIV infection is the persistent belief that marrying a virgin will cure a man who has contracted HIV/AIDS (Radhakrishna et al. 1997; Tinker et al. 2000; Larson and Narain 2001). Younger women in Asia are more vulnerable to this treatment because they are sought by older men, who perceive them to be less likely to be infected with HIV/AIDS (Larson and Narain 2001). Unfortunately, the probability of contracting HIV/AIDS significantly increases as the age of first intercourse goes down and/or the age difference between a woman and her partner goes up (Palloni and Lee 1992). One woman in my study was exposed to HIV because of this belief. Her in-laws deceived her into marrying their son, even though they were aware that he was dying of AIDS.

Belief in fate and karma also influence vulnerability. The accounts of some women in Bombay revealed their religious belief and ideology: whatever they were experiencing was a consequence of their fate, of their actions of former births, of the moral laws enunciated for them. As a result they accepted their life situation unquestioningly. Thus their social beliefs disempowered them and made them vulnerable. Prabha (B.5) was fatalistic about her aunt's deception that led her into prostitution. She said:

***“What was the point in confronting her? If it was not written here (pointing to her forehead) she would not have been able to do this.”***

A fatalistic belief in *karma*, led Aarti (B.1), Savita (B.13) and Usha (B.11) to accept pain and bodily discomfort as a predestined element of their womanhood, and prevented them from obtaining treatment earlier. George and Jaswal (1995) found that poor women in Bombay not infrequently fatalistically accepted sexually transmitted illnesses as an inevitable part of being a female.

It is important to note that while fatalistic beliefs appeared to disempower some women and make them vulnerable during the pre-diagnosis stage, belief and faith were crucial elements that helped sustain some women through the diagnosis stage. That an experience could create weakness and vulnerability and yet give strength may seem counterintuitive. However this paradoxical reality emerged from the lives

of some women in Bombay, and is yet another example of the complexity that marks the HIV/AIDS epidemic.

Finally, concepts of womanhood include obligations that may increase vulnerability to HIV/AIDS. Societal construction of ideal feminine qualities and roles characteristically stress sexual innocence, virginity, and motherhood (Mann et al. 1996). Aditi's (B.2) account poignantly reflected how the feminine ideal prompted her to ignore the advice of the doctor during the pre-diagnosis stage and allowed her to engage in unprotected sex as dictated by her husband. She said:

*"I was checked twice and both times it came negative, so the doctor told us always to use something, but my husband needed a child, so who was I to tell him what to do? ... I did not want him to feel that he had a disease and so I was not ready to be his wife fully."*

**Drug Culture:** Drug use was a key element of social vulnerability for the women in Edinburgh who participated in my study. As mentioned earlier, an increase in the use of injected drugs coincided with the advent of HIV in Scotland, thus resulting in the rapid spread of the virus among drug users in the 1980s. Robertson (1990) estimates that within 18 months of the arrival of HIV/AIDS in Scotland, more than half of the city's injectors were infected with HIV. Many of the women I interviewed in Edinburgh were involved either directly in this drug scene, or indirectly through their partner's involvement, thus making them very vulnerable to HIV. The accounts of Andrea (E.18) and Wilma (E.20) revealed that they were vulnerable because they were involved in the culture of injecting heroin and the chaotic life style that resulted from it. Whereas, the accounts of Susan (E.19) and Marcia (E.26) reflect the vulnerability that arose in their lives during the pre-diagnosis stage since their husbands were imprisoned because of their involvement in this drug culture.

### **Structural Vulnerability**

Structural vulnerability has to do with the forces that render some individuals powerless within their social milieu. This powerlessness increases vulnerability to HIV infection by reducing the individual's ability to refuse participation in high-risk

behaviour such as sexual activity with an infected individual. Powerlessness also increases vulnerability by reducing the individual's ability to manage stressful events when they occur, thus feeding back to individual vulnerability.

The accounts of the majority of the respondents in Bombay and Edinburgh at pre-diagnosis stage demonstrated that they were already acquainted with the 'savagery of life' (van der Vliet 1996a). They also revealed that they were powerless 'as a class' (Wilton 1997), and that, although they did not share either culture or language or racial identity, they shared a social position of disadvantage (Farmer 1996) as well as the unjust structures that perpetuated their vulnerability to HIV/AIDS (UNFPA 2000). The disadvantages of these women isolated them and set them apart, into a world that was defined and bound by their own disadvantage; hence, they seemed to gain some of their sense of identity and community through the experience of alienation and difference (Nixon et al 1997).

The women experienced structural vulnerability because their lives were coloured and constrained by the structures of oppression and inequality, namely, poverty, caste, and a culture of patriarchy in which men dominated, exploited, and oppressed because of their gender (Walby 1990). For some, another source of structural vulnerability was found in their lifestyle or livelihood. These were the women who had been forced into sex work or who lived the lifestyle of chronic drug abuse.

These women's accounts reflected how these structures of oppression marginalized and stigmatised them, leading to feelings of alienation within them. Their vulnerability to HIV/AIDS is inextricably linked to the configuration of the structures poverty, gender inequality (Albertyn 2000), caste, livelihood, and lifestyle that combine to create an oppression that is more destructive and powerful than any one of the structures on their own. The more these oppressive factors converged, the greater was their structural vulnerability. These factors seemed to come together in the lives of many respondents, forming a complex constellation of conditions that placed them in a situation of jeopardy. While the majority of the women in both Bombay and Edinburgh experienced at least double or triple jeopardy, some women

experienced quadruple jeopardy. The multiple experiences of jeopardy and structural vulnerability of the women during the pre-diagnosis stage are discussed more fully under each structure of oppression: poverty, gender, caste system, lifestyle, and livelihood. The concepts of social and structural vulnerability overlap considerably; therefore some issues such as poverty and caste play a role in both.

**The Structural Role of Poverty.** The poverty described by women in Bombay was stark because it arose largely from the physical and economic circumstances of hunger and 'clinging to the edge of survival' (Macionis 1988) and/or from the social poverty that arose from gender inequality and the caste system. The poverty described by some of the women in Edinburgh was also desperate, because it resulted largely from the social, psychological and spiritual (Beresford 1999) circumstances created by human relationships, the damaging nexus of drug use and drug dealing either by the women themselves or by their partners or by the damaging nexus of drug use and sex work.

Nearly all the women I interviewed in Bombay and Edinburgh (with the exception of three) belonged to an economically deprived class. Whereas women in Bombay made a reference to their poverty in relation to being unable to provide for the basic needs of their family, the women in Edinburgh referred to their poverty in relation to being on state benefits. Four women from Edinburgh spoke about poverty in relation to difficulty in procuring money to feed their drug habit.

The Scottish Poverty Information Unit (1997) notes there has been an increase in poverty for all economic groups. However, the concept of 'absolute' poverty, or the inability to satisfy minimum biological needs of food and clothing, is no longer of clear applicability to Britain. The Educational Institute of Scotland's Poverty and Education Report (1998) points out that the concept of 'relative' poverty that encompasses social and cultural factors and the standard of living of a society is perhaps a more meaningful concept. The poverty line is an indicator that provides the national estimates of the percentage of the population lying below the poverty line



are based on surveys of sub-groups, with the results weighted by the number of people in each group.

According to the CIA (2001), the percentage population below the poverty line in India is 25% whereas in the United Kingdom it is 17%. This indicator does not accurately represent the differences in the economic poverty experienced by the women in the two contexts. The actual gap between the experiences of economic poverty in the two countries is far more significant. The reason for this could be due to the fact that the definitions of poverty vary considerably among nations, because richer nations generally employ more generous standards of poverty than poor nations (CIA 2002).

The accounts of some women in Bombay reveal the double jeopardy they experienced because of the intersection of poverty and caste in their lives. Savita (B.13) recalled that poverty had compelled her mother to marry her to a very sick man (who unknown to them had AIDS) several years her senior. She said:

*“ My mother thought that if I was married into a good family, I would get be able to get at least two meals a day, and that I would be far away from my father who is a drunkard, and cannot be depended on.”*

Lakshmi (B.15) and Champa (B.10) both recalled how the poverty of their widowed mothers had forced them to give away their young daughters in an early marriage to men who were sick and several years older than them. Their accounts revealed that in India the poverty of widows is visited upon their children who are uneducated, disrespected, and destined for a life of disadvantage and insecurity and vulnerability (EWD 1999).

The accounts of Wilma (E.20) and Andrea (E. 18) revealed the impoverishment, and the loss of meaning and purpose in life experienced by them, because of their dependence on heroin. Their accounts poignantly reflected the ‘spiritual poverty’ experienced by them. Wilma recalled how, for her heroin use was the epitome of wretchedness, because it destroyed her life and all meaning in it. She described the painful account of how she had injected drugs for so long that she had no veins to



stick the needle into. She went on to explain that although it was hellish not being able to find a vein, no “real junkie” would ever go back to “snorting dope”, so she was forced to inject it in into her muscle. She asked me:

***“How can you live with a vampire inside you that crushes every thing that is decent and robs you of your soul? ... see it is something that destroys you because you didn't know how to live without it”***

Thus poverty made it difficult for women to protect themselves against HIV/AIDS, because often the struggle to survive in the present seemed larger than the struggle to avoid HIV/AIDS. Economic and social poverty made it harder for them to prevent marriages to older men to get medications and to eat well. Drug use impoverished women an inner, deeper level, psychologically making it difficult for them to break out of the vicious clutches of heroin. Poverty with its varied dimensions made the women in both Bombay and Edinburgh structurally vulnerable to HIV/AIDS in the pre-diagnosis stage.

**Gender.** Gender defines a person's opportunities, roles, responsibilities and relationships. While sex is biological, gender is socially defined (Mane 1997). The accounts of the women revealed that women were structurally vulnerable because of a series of power imbalances and inequity between them and their partners or their partner's families. The gender inequality they experienced was rooted in the patriarchal family structures and systematic patterns of male dominance, exposure to violence and abuse, and in the pre-determined, socially constructed roles of women.

Patriarchal male dominance was reflected in the accounts of Champa (B.10) and Cynthia (E.24) and Shirley (E.27) who had hostile and violent relationships with their husbands. Champa recalled how her husband often lashed out at her when he came home drunk, after being with another woman and beat her, invariably on her lower abdomen. She recalled the terror of him forcing her to have sex. She said:

***“He would first hit me and then force me, even if I shouted his brother or mother would not care ... this area of mine always hurts (touching her abdomen) even now, even after all these days...”***

Cynthia recalled how her husband's constant domination and violence wore her down and led to her injecting drugs with him, to overcome the constant hurt and suffering that he inflicted on her. She said:

***"I was so absorbed in forgetting the pain that I didn't allow myself to see what was happening. Looking back, I see now that the only way I could continue living was by pretending that it was not me it was happening to. I knew there was something incorrect, but I feared facing truth. So I didn't. Instead I started injecting with him."***

Moreover, the influence of patriarchal family structures was also present in the accounts of a few women in Bombay who had antagonistic relationships with their in-laws. From their descriptions, emerged a scenario where it was not the husbands, rather, only the in-laws who exerted this power. Situations where women oppressed women, where the traditional patriarchal structure within the joint family created a power structure that not only paralleled male power (Mbugua 2000) but also at times even superseded it. A chasm of mistrust and a power struggle between mother-in-law and daughter-in-law were evident in the accounts of Namita (B.3), Rashida (B.12), Savita (B.13), Priya (B.14) and Lakshmi (B.15).

Namita (B.3) recalled how she discovered that her husband and his brother's wife had an ongoing relationship and a child from that relationship until she was married, when her mother-in-law openly taunted her about it. She remembered how on her wedding night, the 8 year-old boy was sent by her mother-in-law to sleep between the two of them. She sobbed as she recalled all the naked cruelty unleashed on her by her mother-in-law and sister-in-law because she was very dark skinned and came from a lower caste compared to her husband's family. Moreover she had to remain silent about the injustices because gender inequity is socio-culturally condoned in India; therefore, her husband was granted sexual freedom, whereas she could not question him or his family because of traditional constraints (Larson and Narain 2001).

The patriarchal power structure in the lives of women in Bombay appeared to base its legitimacy on the fact that the 'in-laws' were the husband's family and needed to be revered. This extended even to occasions where the obligation impaired women's

the fundamental human rights to food and to respect as a human being. Lakshmi (B.15) recalled how both her mother-in-law and sister –in-law, beat her in front of her children and called a prostitute on the smallest of pretexts, but accepted it as part of family life.

Savita (B.13) and Priya (B.14) both recalled how their mothers-in-law used food to exercise their power over them. Their accounts also revealed their silent, yet complete acceptance of the abuse they faced, because it came from their husband's families. Savita recalled how her mother-in-law made sure that she was never given enough sugar and milk in her tea, because she liked it sweet and milky; and how she was the only person in the family never to get any sweets or snacks that came into the house. Priya recalled how her mother-in-law forced her to eat food that was stale and sometimes even spoilt. She recalled this unjust treatment with tears in her eyes and said:

***“She would force me to eat it, but I never dared to disobey, she was my husband’s mother, even then she would scream: you ‘bhangi’ (women who clean excreta) I know what food your parents used to feed you.”***

The mother-in-law is often an enemy for women in similar circumstances. Marriage into families that breed patriarchy and allow the traditional pattern of man's power over women is a source of women's oppression (Millett 1970; McElroy 1996). Moreover, the reality of patriarchal family structures and gender inequality appear to be the overarching reason for women's secondary position within marriage and society and a major cause of gender based violence, because patriarchy requires violence or the subconscious threat of violence in order to sustain itself (Steinem 1992).

The socially constructed role of the women in this study was characterized by gender inequality in which women had less power than men. As discussed earlier in this chapter, the accounts of women in Bombay and Edinburgh revealed that the imbalance of power between women and men limited them from protecting themselves. Aditi (B.2) believed that she had to allow her husband unprotected sex, because he wanted it, despite the advice of the doctor. Andrea (E.18) and Wilma

fighting and swearing of a few men, and a strong, almost unbearable stench of rotting rubbish. She said:

***"I began to feel sick in my stomach; I had not eaten for over 10 hours. I asked my relative where we were going, and she just kept walking ... I started to feel very giddy. I fainted".***

Vulnerability is very high in coercive circumstances where women are trafficked into prostitution (UNIFEM 2001). Piot (1999) points out that according to United Nations estimates four million people are trafficked every year. Prabha's (B.5) account highlights the intersection of gender, poverty, low caste, violence and trafficking.

The vulnerability of two women was expressed by internalisation of the stigma and discrimination they experienced. Wilma (E.20) pointed out that people were not to blame for their negative attitude towards women who 'prostituted' themselves. Prabha (B.5) also suggested that she did not blame people for looking at her with hatred. She said:

***"It is not their fault that they behave that way, I would also look at a person from the gutter in the same way".***

Sex work brings with it violence, criminalisation, stigmatisation, reduced civil liberties and rights of human dignity, as well as the risk diseases (O'Neill 1996) and vulnerability to HIV/AIDS. The accounts of women in my study bear out the finding that male violence against female sex workers is endemic (Barry 1979; Hoigard and Finstaad 1992; O'Neill 1992). All three women spoke about the sexual violence they experienced at the hands of their clients, pimps, and sometimes even their partners or lovers too. Their vulnerability lay in the irony of the fact that they were criminalized and stigmatised by the very services that were critical for their protection; inhibiting them from using mainstream health services, or contacting the police.

In fact, the police may be a source of threat for women in sex work. According to Amnesty International (2000), police custodial violence against women is very common. They suggest that thousands of women held in custody are routinely raped in police detention centres worldwide. Human Rights Watch (2002) described the

shocking violence perpetrated by the police in India, not only on sex workers, but also on HIV/AIDS workers. The same Human Rights Watch report points out that the police often arrest health workers on suspicion of being sex workers because they have condoms in their possession. The practice undermines the country's efforts to contain the spread of HIV/AIDS and renders women even more structurally vulnerable.

Andrea (E.18) and Wilma (E. 20)'s accounts highlighted various aspects of the structural vulnerability of women in Edinburgh in the early 1980s who pushed heroin and crack cocaine. They pointed out that heroin and cocaine were always found in the poorest areas of a city, and that the individuals who dealt in heroin on the street were usually the same individuals with the habit to feed.

Wilma (E. 20) said that it was almost inevitable that drug users turned to sex work, crime, thieving, and dealing in drugs in order to get enough money to feed their habits. She said:

*“Heroin is the hell that eats into your soul ... you were forced to push smack ... junkies need to get the money from somewhere for their fix ...”*

The accounts of these women also emphasized the rough treatment of the police, and the viciousness of the Drug Squads who criminalized them, as discussed earlier in this chapter. Wilma recalled how she was slapped, kicked, punched and thrown on the floor, and the only way she could bear to cope with that humiliation was by “going into a heroin stupor”, that numbed the pain, until she was forced by the chemical dependency of heroin to get moving.

**Marginalisation, Stigmatisation and Alienation.** The Oxford Concise Dictionary (1995) defines 'marginalised' as 'made or treated as insignificant' or 'to be relegated or confined to a lower or outer limit or edge, as of social standing'. The term 'marginalisation' is derived from the word 'margin', that is, 'to be on the edge' (Webster 1995). Uchem (2001) points out that 'margin' is connected conversely to space and freedom, in terms of scope, franchise and self-determination, in the sense of being unlimited and unconditional. Therefore, to be marginalized is to be limited



in scope, space, freedom of operation, and the right to self-determination. Marginalisation as a lived experience generally involves exclusion, discrimination, rejection, omission, and isolation. Marginalisation is a method of creating and preserving social identities and individual self-definitions affecting individuals at all levels of society, which entails developing a dominant social identity against the conditions of the excluded individuals and social groups (Estes et al 2000).

As mentioned in chapter 2, the "excluded ones" or those living at the margins, who were marginalized even before the advent of HIV/AIDS in their lives, are the ones who are most affected by HIV/AIDS (Mann et al. 1992). One thing marginalized groups have in common is an increased vulnerability to HIV/AIDS (UNAIDS 2000).

Andrea (E. 18) recalled how in the early 1980s in Edinburgh, she could never go to doctors because they never believed that her complaints were genuine. Instead, they always thought that drug users were deviously trying to obtain drugs for them. She pointed out that if you were a drug-user you were thrown out of the surgery. Moreover, once when she had an accident, and broke her ankle, she went to the Accident and Emergency Clinic, where she was treated very suspiciously, and even told that there was nothing wrong with her ankle. She recalled how she went to them thrice on one day, because the pain was so unbearable. Instead of being treated, she was put into a police lock-up.

The word stigma has its etymological origins from the Greek word "to brand, dot or mark". It was used for runaway slaves, and was therefore extended to embrace "any mark or sign for perceived or inferred conditions of deviation from a norm" (Weiner 1995). Goffman (1963) points out that stigma is a "significantly discrediting" attribute possessed by persons (such as low caste women, homosexuals, drug users and sex workers) with an "undesirable difference". It is a powerful disgraceful and tainting social label that completely alters the way individuals view themselves and are viewed as individuals (Gilligan 1996). Additionally, the stigmatised are a category of individuals who are unconstructively looked upon by the broader society and who are devalued, rejected or otherwise lessened in their life chances and in access to the humanizing benefits of free and unencumbered social interaction



(Alonzo and Reynolds 1995). Stigma is an expression of social and cultural norms that shape relationships among individuals according to those norms; and marks the boundaries a society builds between "normals" and "outsiders," between "us" and "them", and feeds on cultural differences to block out common humanity (Gilmore 1994). While the societal rejection of women belonging to these social groups predates HIV/AIDS, the advent of HIV/AIDS has, in fact, reinforced stigma about women, making them deviants or shameful. Thus, leading to their greater shunning, avoidance and rejection, and rendering them even more structurally vulnerable.

Moses (1997) points out that often stigmatisation affects individuals who are already marginalized in a number of ways, creating feelings of unworthiness, inadequacy, and powerlessness. The accounts of some women in Bombay and Edinburgh reflected their feelings of alienation during the pre-diagnosis stage. Women in Bombay who belonged to a low caste were particularly powerless in the face of the oppression they experienced from their in-laws. Champa (B.10) recalled how physical and mental abuse against her was a norm rather than an occasional occurrence. The mental abuse included taunts about her dead parents and spouting out worms from her mouth, which she found extremely painful to bear. She spoke about her feelings of total powerlessness. She said:

*"If it was not my mother-in-law cursing me, it was my sister-in-law or my husband or his brother ... they would malign them (her parents) even more, and curse me 'you prostitute close your mouth, don't let the dirty worms out into our home ... I felt so on my own and helpless.'"*

Women in Edinburgh described the feeling of powerlessness; isolation and meaninglessness visited on them by the structures of gender inequality and abuse, sex work and drug use. Wilma (E.20) recalled that the intense abuse she had experienced from her partners and from heroin dealers left her feeling disassociated from herself. Her feelings of helplessness and loss of control, she said were a constant reminder that she had little or no control over her life or body and this isolated her, and made her feel very alone.

Jasmine (E.17) recalled the complete powerlessness she experienced when she was raped. She suggested that when she recalled that harrowing experience, she relived it and even talking about it renewed her sense of powerlessness. She said that the feeling of total powerlessness was difficult to express adequately to someone who had never experienced it.

Marcia (E.26) recalled the deep feelings of isolation she experienced after her husband was imprisoned because he was caught dealing in drugs. She also recalled the complete meaninglessness she experienced because a member of a drug gang mistakenly murdered her brother whom she believed to be totally innocent.

The lives of women in Bombay and Edinburgh during the pre-diagnosis stage reflected how the structures of oppression, impinged on their lives and marginalized, stigmatised and alienated them, rendering them structurally vulnerable. The result of these experiences is a sense of powerlessness, which can reduce the individual's ability to engage in self-protective behaviour. Some of the women in my study may have become infected with HIV because they no longer had the will to take steps to protect themselves. They thought of themselves as worthless non-persons, and thus did not act to preserve their own well-being.

## Conclusion

The material presented above illustrates the three ways that the women in my study were made vulnerable to HIV/AIDS. Their histories of trauma and abuse reduced their ability to protect themselves, by lowering their expectations that they could and should be entitled to safety and physical integrity. Their histories of disadvantage and poverty reduced their resources to protect themselves, by limiting their access to necessary information and materials that would enable them to avoid infection. Finally, their histories of stigmatisation and marginalisation reduced their power to protect themselves. For these women, it was unthinkable that they should stand up for themselves or indeed have any say in the course of events that led to their infection with HIV.

## CHAPTER 6: THE DIAGNOSIS STAGE

### Introduction

This chapter describes the next stage of diagnosis in the women's lives. It covers a comparatively shorter time frame than the pre-diagnosis and post-diagnosis stages. The diagnosis stage discussed in this chapter begins at the point when women were asked to be tested or decided on their own to be tested, and it extends through the few months that followed positive diagnosis. The idea here is to focus on the diagnosis and its immediate impact, before much time has elapsed to allow for adjustment. The ensuing adjustment period will be discussed in the following chapter. It is important to emphasize that the stages of pre-diagnosis, diagnosis and post-diagnosis used here are broad time frames, rather than specific time periods, and that the boundaries of the three stages are somewhat fluid.

The key issue for this stage concerns the immediate impact of an HIV/AIDS diagnosis. How did the news come to the women in my study, and how did they react? The first part of this chapter explores the reasons why the women came to be tested and their feelings and thoughts about being tested. It next examines the women's immediate reactions when they first received their positive diagnoses. This section also examines the behaviour of the medical professionals who gave them their diagnoses and the reactions of family and friends with whom they shared their diagnoses.

The next section explores the women's first experiences of living with a positive diagnosis, including what they felt, thought, and feared during the diagnosis stage. It presents the main assertion that developed from the women's accounts of the diagnosis stage and throws light on the life experiences of the women during this stage. The assertion for this stage focuses on the predominant emotional reaction to an HIV/AIDS diagnosis. It states that anger, similar to that described in Kubler-Ross's second stage (Kubler-Ross, 1969), was the emotion most commonly

experienced and reported by the women after they received a positive diagnosis. The chapter concludes with a summary and points to the next chapter.

## Getting Tested for HIV

### Reasons for taking an HIV Test

The women's accounts revealed that the majority of women (22 out of 27) in both Bombay and Edinburgh were tested because their doctors advised them to do so. Physicians asked the women to get tested for HIV/AIDS when the women consulted them for other medical concerns. They reported three main reasons why testing was suggested: their own illness or nagging health problems, the illness and/or positive diagnosis of their partner or child, or pregnancy.

The reactions of women who were referred for testing in these circumstances ranged from a total lack of awareness that they were at risk to panic at the thought that they had been exposed to HIV. The level of knowledge about the disease and the risk factors for HIV was quite variable among the women in my study, and this reflected in their reactions to being tested.

Among the women who reacted calmly, the reaction of Urmi (B. 11) is typical. She was tested because she suffered from genital warts (or dysplasia, a common occurrence in positive women). Although she was told why she was being tested, she did not believe she was at risk and therefore said that she never gave testing much thought:

***"I went for the blood test, because I was told to. I did not think of anything or worry about anything."***

For many of these women, the notion of HIV was very abstract and foreign to them, and they did not realize the implications of being tested. Kumud (B.7) recalled that it meant nothing to her when the doctor asked her and her husband to get tested for

HIV. She thought that it was one of the many tests that she and her husband had undergone since they were both diagnosed with TB. She said:

*“The doctors rattle off the names of so many tests, what can people like us understand? HIV test meant nothing at that time to us; how were we to know it was such a deadly illness?”*

Her feelings were echoed in the accounts of a large number of women in Bombay, many of whom had little education or awareness about the illness. My experience matches what Chase and Aggleton (2001) found in India. They found that at times women gave consent without fully comprehending the implications of a test, so there was in effect no informed consent given.

Even among those who had reason to know about HIV/AIDS, the understanding of their personal risk was curiously limited. Despite the fact that they already knew about HIV because their partners or child were diagnosed with it, they still did not seem to understand that they had been exposed to the virus. It appeared that, although these women believed that they understood how HIV was transmitted, their actual comprehension was somewhat limited.

Nisha's (B.8) account is a good example that reflects the experience of some women in both contexts. Although she understood that HIV was sexually transmitted, she experienced a level of denial and a limited understanding of her true risk. She recalled that she opposed taking the test, because she was a married woman who had never been promiscuous. She did not seem to realize that she could contract the disease through her husband, and may also have resisted accepting the idea that he had had other sexual partners. Lack of reliable information and the presence of misinformation may also be contributing factors for some of the denial and doubt expressed by these women.

At the other end of the spectrum are women who were aware of and very concerned by their risk for the disease. Julia (E.16) and Belinda (E.22) decided to undergo HIV testing on their own initiatives. Julia (E.16) decided to get tested for HIV because she

was becoming quite worried about her poor health, loss of weight, and symptoms that she could not quite understand. She believed that, because her boyfriend had betrayed her and had been in a relationship with somebody else simultaneously, there was a risk factor involved. She said:

***“I decided that I had to know as soon as possible ... I realised that there was a distinct possibility that he had been having promiscuous sex with a lot of other women all over the world, and that there was perhaps a chance that I had contracted some sexually transmitted disease or HIV through him.”***

Belinda (E. 22) recalled her decision to get tested as soon as her boy friend told her about his own diagnosis. She said that she was the kind of person who needed to know exactly what she was dealing with, and therefore immediately got tested.

A few women had no opportunity to choose whether or not to be tested. Four women in Edinburgh were tested without their consent because they were drug users. This occurred in the early days of the epidemic in Scotland. Molly's (E. 21) diagnosis was “delivered” to her by her Consultant while she was still on an intravenous drip and recuperating from an obstetric procedure she had undergone the previous day. She used the words “out of the blue” to describe just how unexpected and unprepared she had been about being tested and diagnosed for HIV. Allison (E.23) discovered that she had tested positive for HIV when she went in for a pregnancy examination and was thrown out of the ward by the nurse who screamed out her diagnosis. She believed that she had been tested without her consent because she had been an injecting drug user, and felt cheated and helpless. She said:

***“They know fair well that they aren't meant to be sneaking up and testing you, without yours consent and all that, but in they days they dinne care; saw a junkie and they took the law in their own hands. There was little you could do in they days.”***

Cynthia (E.24) recollected that when she went in for a minor breast surgery, a nurse told her that she had been diagnosed positive two years earlier. She recalled being upset that she had been tested without her consent two years earlier when she was



pregnant, just because she had occasionally injected drugs. She said that it was only at that point that she understood why the Consultant at the time had half-heartedly suggested she terminate her pregnancy, without giving her any reasons. Although she never said anything at the time because she had too much to cope with, she felt violated.

Wilma (E.20) discovered that she had been tested for HIV and was positive when a doctor in the women's prison, where she was serving time, told her that she had cervical cancer, that she was allergic to her boyfriend, and that she had two years to live all in one breath, very matter-of-factly. She said the fact that she was positive did not really seem to register or hold any importance in comparison, with the fact that she had cancer and only a short time to live.

The accounts of these women from Edinburgh all reflect the marginalisation and disregard for basic human rights that they experienced as drug users. These women were not allowed to choose whether they were tested, and some of them were not even given timely information about their diagnoses, thus depriving them of the ability to take better care of their health or even to prevent further spread of the infection.

## **Receiving a Positive Diagnosis**

**Personal reactions.** The women reported immediate reactions that ranged from crying out to silence and from emotional shut down to denial. It should be emphasized that eleven women in Bombay already had the experience of HIV in their lives before they received their own diagnosis, because their husband, fiancé or child had been diagnosed with HIV/AIDS. This knowledge inevitably coloured their reactions to the diagnosis, but their reactions were not substantively different from those of the other women. Seven out of these eleven women discovered their own diagnosis within the first week of discovering their partner or child's diagnosis. This meant that they had not really had the time to understand and synthesise the gravity

of this new illness. Moreover, their knowledge of the illness itself was very limited, and they were only just beginning to understand something about it.

The majority of the women in Bombay recalled crying out as their immediate reaction to receiving the news that they were positive. These women described their reactions as “crying and crying”. Namita (B.3) recalled crying so much that she became unconscious.

Only two women in Edinburgh, Jasmine (E.17) and Molly (E. 21) recalled crying openly when they received their diagnoses. Although many other women from Edinburgh recalled crying and weeping, it was done later in the privacy of their own homes. This contrast between the women of Bombay and those of Edinburgh seems to reflect a number of differences between the two cultures. For the women in Bombay, who were raised in a more traditional culture, crying seemed to be a more acceptable and normal response. For the women from Edinburgh, raised in a modern urban culture, a more private, clinical reaction seemed to dominate. The women of Bombay may also have been reflecting the very desperate situation they faced, where an HIV diagnosis could mean financial ruin or suffering in the way they had seen their partners suffer with AIDS. Their poverty and general powerlessness may also have led them to the helpless response of crying. Two of the women, Namita (B.3) and Aditi (B. 2), knew that they were going to have to put on a façade of normalcy once they went home, so perhaps that was the reason why they cried so openly when they had the opportunity to vent their feelings.

Some accounts revealed immediate reactions of silence and emotional shut down. Aarti (B.1) recalled that although she felt like crying and screaming out but nothing left her lips. She said:

***“I was screaming from inside and howling, but not a word left my lips, not a tear came to my eye. I felt like I was a stone from inside, nothing could move me, I felt like a statue”***

Aarti’s (B.1) daughter had been diagnosed with AIDS barely 48 hours before she got the confirmation that both she and her husband were positive. She may have been in

too much of a state of shock to cry. In fact she used the phrase “struck by lightning” to describe her reaction.

Kumud (B.7) and her husband received their diagnoses together. He was very frail in comparison to her, although they were both suffering from TB. She had lived through a horrific burns accident when she was pregnant with twins; at which point she and her unborn twins became infected through a blood transfusion. She recalled that when the doctor told them about their diagnoses, he pointed out that the twins might be infected as well. At that moment she said:

***“the ground under my feet started to shake, I felt like I would fall down, my husband had tears in his eyes, because he had become very weak by then ... I could only think of my innocent, rose-like babies.”***

Kumud’s outward calm may also have reflected survival needs. She may have felt the need to keep her own feelings in check in order to help her husband and her children.

Two women reported reacting to the news of their HIV-positive status by exhibiting behaviour that could be characterised as denial. In the case of Urmi (B.11), acceptance seemed to reflect her cultural belief in *karma*, but may also have been related to her grief over losing her daughter. She reported feeling sad, but said that she did not cry or react openly, remarking that contracting HIV was her *karma* and she accepted it. Urmi’s calm, fatalistic approach was reflected throughout her interview, which took place only six months after the death of her seven-year-old daughter. This loss may have allowed her to put her own illness in perspective, or perhaps her reactions to losing her daughter coloured her recollections of her earlier reactions to her own diagnosis.

Earlier losses also seemed to influence Susan’s reactions to her HIV diagnosis. Her mother had recently died, and her father was seriously ill at the time of Susan’s (E.19) diagnosis. Within a few weeks, her husband, who had just been released from prison, also died of AIDS. Susan seemed to accept her diagnosis and focus on the needs of her father and of her infant son. She reported:

***“I was not shocked or upset. I said right, I have got it, I will just have to get on with my life, and that is just what I have done. “***

The majority of the women in both Bombay and Edinburgh recalled thinking about death, dying, and the end of life, when they first mentally registered or understood the concept of HIV and AIDS. Leela (B.6) recalled the deep pain she experienced at the thought of leaving her child an orphan, especially since both she and her husband were orphans themselves. Parul (B.4) and Aditi (B.2) both recalled that, albeit their shock and sadness when they received their diagnosis, they experienced a brief sense of relief, that they too, like their partners, were now HIV/AIDS positive. Parul recalled that initially all the pain she felt was only for her fiancé, and she unrealistically believed that, now that both of them were positive, they could marry, live together, and die together.

Both Parul and Aditi were in relationships for the first time, and they were very much in love. Parul was only 16 and engaged to be married, whereas Aditi was much older, nearly 30. Also, they were both socialised in the Indian culture that believes and inculcates the ethos of *Pati Parmeshwar* (literally, “husband is God”). They both seemed to have a magical sense of consciousness and a simplistic view on life, and at the moment when they were given this grave news, their way of thinking seemed to protect them from the gravity of their situation.

It is curious that none of the 27 women actually described their initial reaction as denial or disbelief. A large number of the Bombay women had already been informed that a partner or child had a positive diagnosis, and they may have already formed some idea that they themselves could have HIV/AIDS. It is also possible that their initial reactions were so coloured by shock that they did not immediately experience something they would describe as denial. Kubler-Ross (1969) notes that denial is an important part of the grief process, but it may come later, after the initial shock of discovery has worn off.

**Reactions of medical personnel.** The accounts of the majority of the women in Bombay and Edinburgh revealed that the medical professionals were sympathetic,

patient, and understanding towards them. However, two women in Bombay and six women in Edinburgh recalled having negative experiences, some particularly negative. As discussed earlier, women in Edinburgh who used drugs had particularly negative experiences with medical professionals even before the advent of HIV/AIDS in their lives.

Aarti (B.1) recalled her complete shock when she and her cousin were told of her child's diagnosis with AIDS. This occurred in the ward of the hospital, where her daughter was being treated for kidney problems, and where very little privacy was available. The doctor announced all in one sentence, without taking a breather, that her child was very sick, had AIDS, that they needed to be moved out of the ward into a special unit for highly infectious people immediately, and that she and her husband almost certainly had AIDS and had to be tested the next morning. This lack of regard for confidentiality was apparently not unusual in the case of HIV diagnosis. Bharat et al (2001) found that hospital staff often revealed the serostatus of the patient to their relatives, without taking the patient's prior consent.

Prabha (B.5) recalled the cruel and inhumane attitude of the nurses, who were preparing her for a gynaecological examination by the doctor, soon after she had been given the news that she had the "bad blood illness". She cried as she told how the nurses stood as far away as possible and touched her as if they were touching something filthy. The majority of the other women received their diagnosis in ARCON, and were therefore protected from the stigmatisation and discrimination that women commonly face in large hospitals in Bombay and other parts of India.

The treatment received by a few women in Edinburgh was particularly poignant and reflected the ignorance and the stigma that prevailed in the early 1980s. Jasmine (E.17) recalled the manner in which she received her positive diagnosis. She was pregnant at the time and was called for a "short discussion" at the maternity hospital. This short discussion was to tell her that she was positive. The doctor stated that there was a fifty-fifty chance that she would not survive the pregnancy, because pregnancy could aggravate the diagnosis. He left her in a small room and asked her if she wanted a cup of tea. She was to let him know if she would take his advice and

have a termination. So unprepared and vulnerable was she that she decided for the sake of her one and half year old son to take his advice and underwent a termination. However, this decision affected her very negatively. She said:

***“I had been and still am a pro-lifer, believing in the rights of unborn children. So after having this termination where I had no counselling or advice, I was manically depressed.”***

Molly (E.21) recalled at some length the moment when she received her positive diagnosis. She was in hospital because she was suffering from a pelvic inflammatory disease and had gone in for some routine examinations. She had just recently undergone the procedure and was rather weak and being administered an intravenous drip, when a Consultant, or a person she referred to as ‘a figure’ came and half opened her door and asked her to confirm her name and date of birth. After he confirmed her name he stood in the door and told her that he had some bad news for her “you have AIDS” and having said that he turned around and slammed the door and left her on her own to deal with the news. The year was 1985. Her description of the way in which the doctor was dressed, clearly reveals the high levels of fear and stigmatisation that existed in Edinburgh at the time. She said:

***“All I could see was a pair of glasses, a moustache, a part of a beard. Other than that he had a hat on; he had a mouth mask like they ones they wear in the operation theatres. He was covered in gowns from the operation theatre, head to toe and had gloves and protective footwear too.”***

Andrea (E.18) and Allison (E.24) were both asked to leave the hospital as soon as they were given their diagnosis. Andrea was given her one line diagnosis: “You have AIDS”, and was given an hour before she was shipped away from the Royal Infirmary to an infectious unit by ambulance. Allison’s diagnosis was screamed out at her in front of a waiting room full of patients. She recalled the trauma and terror she experienced when she went in for a routine pregnancy examination, and was instead told that she had AIDS and that she should not infect the ward. She recalled the behavior of the nurse who delivered her diagnosis:



*"She was hysterical, plain hysterical and screamed my name and date of birth out twice at the top of her voice: 'geet oot, oot', and she was red in the face and fumin' ... 'I said oot ... I'll have to close down my ward and scrub it oot thanks to ye'."*

**Reactions of family and friends.** The women's accounts in Bombay and to a lesser extent in Edinburgh revealed that the stigma that was often associated with HIV/AIDS made it rather difficult for women to share their diagnosis with loved ones. Many women struggled with whether or not to share their HIV/AIDS status with family, neighbours, and friends. Those women who had not shared their status spoke about their great fear of rejection and lack of understanding, as well as their unwillingness to burden loved ones with such news.

The reactions from families and friends in both contexts ranged from very supportive to ostracizing and inimical. The mothers and siblings in both settings, and the brothers in Bombay particularly, were very supportive towards the women when they received a positive diagnosis. Urmi (B.11), Rashida (B.12), Parul (B.4), Andrea (B.18) all described the support and affection their mothers had given to them immediately after they were diagnosed. These women's accounts seemed to suggest that the women's mothers were more deeply grieved than their daughters. For example, Urmi seemed very balanced about her own diagnosis, and Andrea accepted the inevitability of her diagnosis, while their mothers reacted strongly. All the women recalled how their mothers cried. Parul (B.4) recalled how unreal everything seemed the evening when she and her fiancé, returned with her positive diagnosis. Her fiancé had been literally thrown out of his home the week before when he disclosed the truth that he had AIDS. She recalled how everyone in her home started crying when they heard the news.

The accounts of Julia (E.16) and Jasmine (E.17) tell a different story about experiences with their families, particularly their mothers. Julia spoke at some length about her parents, and especially her mother. Dealing with her diagnosis had brought up many issues about her youth and childhood that she had managed to resolve through therapy as a young adult. She was at the time of the interview debating how

to disclose her positive status to them. She spoke very eruditely about families, their need to protect each other, and the conspiracy of silence and denial that exist in many families. She recalled her childhood as being pretty complex because her mother was rather sickly, and was very much a hypochondriac. She spoke very expressively and openly about the dilemma and pain she was experiencing.

***“I’ve been strong for her; there have been times when the relentless neediness of it all has got to me, but no I have been there for her, it is not about payback time... it is about honesty. This is my reality, and I want you to know the truth and acknowledge it”***

This account poignantly reflects the intense soul searching and complexities that HIV/AIDS brings to already complex, intense lives.

Jasmine (E.17) recalled with pain the “viciousness and the ostracism” she had experienced from her mother when she shared her diagnosis with her, and how her mother moved the courts to take away her child from her. She also recalled how differently her friends reacted, to the news, one made it a subject of gossip, whereas another assured her of her love and trust. She said she felt honoured by the care and trust her supportive friend gave her.

Savita (B.13) recalled that she was terrified of anyone other than her brother and mother knowing about her diagnosis. She movingly explained the reality of societal expressions towards positive persons. She said:

***“I do not feel that I will ever let any one know about it. We understand that the illness is not contagious, but some people feel that by just only looking at a HIV person, they will get ill.”***

Both she and Namita (B.3) reported that their brothers were extremely supportive to them. Namita’s brother cared for the physical needs of her husband when he was very unwell. Savita’s brother swore not to marry until Savita was cured, because he believed that if he married, his wife might not be as sympathetic and caring towards her.

The abuse and ill treatment of some women in Bombay by their in-laws was highlighted previously. These women were rejected, blamed, and stigmatised for infecting their husbands, even though they were in reality the innocent ones. Many of the women in Bombay described their relationships with their husbands or in-laws as unstable following the HIV/AIDS diagnosis. Although the husbands and their families were aware of the role the man played in the transmission of HIV/AIDS to their wives and daughters-in-law, they often struck out in anger and blamed the women for bringing HIV/AIDS into their lives, as was reflected in the accounts of Champa (B.10), Lakshmi (B.15.), Priya (B.14) and Rashida (B.12). Rashida's in-laws treated her like an untouchable when she tested positive, although her husband was still alive. She was made to do all the menial work in the home and was not allowed to sleep with her children, who were barely one and a half and three years old.

An HIV/AIDS diagnosis brought new complexities to the marital relationships of many of the women. For three women in Edinburgh, the relationship with their husbands was altered by the husband's denial of his own role in transmitting HIV. Susan (E.19), Cynthia (E.24) and Marcia (E.26) revealed that their husbands, (who were probably responsible for infecting them), neither acknowledged that they were positive themselves, nor that they had a role to play in the infection of their partner, nor were they supportive in any way to their wives when the diagnoses were revealed.

Susan (E.19) recalled that although a prison social worker had told her that her husband had AIDS, he completely denied the fact. She did not pressure him to admit it for two reasons. First, she had barely been married a few months when he was imprisoned for a drug offence, and second, she did not know that HIV/AIDS was heterosexually transmitted. Cynthia (E.24) recalled that her husband became more violent toward her after she revealed her diagnosis to him. Not only did he completely deny having any role to play in her diagnosis, but also, he abused her more openly. She believed that it was his way of covering up his own fears about being positive.

On the other hand, several women in Bombay recalled the deep sense of regret and grief that their partners expressed to them, when they discovered that they had infected them and their child Aarti (B. 1), Aditi (B.2), Namita (B.3), Parul (B. 5), and Leela (B. 6) all recalled how their partners wept unashamedly. Leela's husband broke down and sobbed like a child in front of the doctor. Parul's fiancé and Namita's husband touched their feet begging their forgiveness. These reactions were very unusual for Indian males, who are socialised to feel dominant and superior to women. For most men in India the thought of touching a woman's feet, other than those of your mother or grandmother or a revered older woman, is unthinkable. But the advent of HIV/AIDS had affected their psyches so completely that they displayed this uncharacteristic behaviour.

## Beginning to Live With a Positive Diagnosis

### Early reactions to diagnosis

This section discusses the lives of the women in the days and weeks that immediately followed the discovery of their positive status. Living with this newly acquired diagnosis gave rise to a range of emotions, such as sadness, pain, helplessness, despair, hopelessness, grief, loss, anger, and fears about death, dying, and sickness.

The accounts of several women revealed how being so closely involved in the care of their husbands affected their perception of HIV/AIDS in their own lives. They viewed it as a painful, terminal illness, although most of these women were still asymptomatic themselves. This image of HIV/AIDS as a killer was reflected in Savita's (B.13) very graphic description. She said:

*"Dear God, I wouldn't wish that death on any one, not even on her (referring to her mother-in-law) my worst enemy. HIV is a hungry illness, it eats up a man."*

Rashida (B.12) described HIV/AIDS as the wrath of Allah. She said that such a painful illness was the result of some big mistakes for which Allah was angry and could not forgive a person.

Kumud (B.7) and Leela expressed fears about leaving their children orphaned. Kumud recalled that in the days and especially the nights that followed her diagnosis she grieved about her husband's failing health and imminent demise and the poor health of one of her twins. She was crying as she narrated the pain she had lived through. She said that she found it difficult to sleep and that when she did manage to get some sleep, she would awaken with a horrible feeling of fear. She told me:

***"Somehow during the day I could keep myself busy, but when the night came, I would cry myself to sleep.... Sobbing into my pillow so that the children would not hear me. My husband would sometimes turn and put his hand on me and say in a very pained voice "enough, enough, now go to sleep", but the thought of my baby dying was eating me from inside. "***

Sadness and pain were commonly expressed immediate responses to diagnosis. Prabha (B.5) spoke about the intense sadness she felt because her life had come down to such a sorry level. Her inability to change the course of her life and, and by extension her little baby daughter's, provoked a deep sense of pain, sadness and self-recrimination. Belinda (E.22) stressed the fact that she was only 16 when she experienced the enormity of receiving a positive diagnosis. She recalled that she felt her life was over.

Fear was another emotion commonly expressed by majority of the women. They reported fear of dying, fear of pain, fear of illness, and, particularly, fear of HIV/AIDS. This fear was based on their experience of HIV/AIDS in the lives of their partners, or on the images they already had from the media of what it was to live and die with HIV/AIDS. They also experienced fear of losing control of their life as well as isolation, stigma, and abandonment. Champa's (B.10) account reflected these fears. She said that she was living with the constant fear of her HIV/AIDS status being revealed. She was actually trembling when she talked about this. She repeated

the fact that she was terrified of becoming destitute. Janetta (E.25) spoke about her fear of pain at several points during the interview. She felt emotionally incapable of bearing any pain.

The accounts of several women in Bombay and Edinburgh revealed feelings of helplessness, hopelessness, and despair in the days that followed the discovery of being positive. Women recalled feeling hopeless, because they felt they had no way to change their situations. Savita (B.13) recalled that she felt so hopeless because there was no way to express her feelings of being cheated. She had considered talking to her in-laws, but felt was advised by her brother to consider that a closed chapter. She said:

***“If I could have at least fought it out with them, I would not have felt this cheated and helpless. They have just gotten away with it ... My brother says that they are such shameless people they will only gloat at my loss, and then the whole world will know”***

The accounts of Urmi (B.11) and Andrea (E.18) reveal the fatalism they experienced, in response to their diagnosis. Urmi accepted it as the will of God, and therefore went about her daily tasks, including looking after a sickly child. Andrea, who was still using heroin during the diagnosis period, said that she comforted herself with the thought that death was inevitable and that she would be delivered from the anguish and suffering that she was experiencing, even before she was diagnosed. She said:

***“I just thought that I am soon going to die. It did not really affect me, because I was sick of the life I was living, but I felt lonely and isolated. Maybe death would have been nice to get away from the life I was living, eh. Maybe dying would not have been all that bad after all, because I thought I was going to die any ways”.***

Women in both contexts spoke about feelings of loneliness, rejection, and withdrawal. Many women indicated that they felt very alone. These women lacked any social support or family support. Marcia (E. 26) recalled the tremendous loneliness she experienced during the diagnosis stage. She said:



***"I have never felt so utterly by myself, even though the bairns were there, I felt so alone."***

Jasmine (E.17) echoed Marcia's sentiments. She too recalled feeling very isolated, because of the manner in which she had been treated by her family and friends.

Several women reported receiving support from their families or from social service agencies devoted to serving people who are HIV positive. Meera (B. 9), Leela (B.6), Julia (E.16), Janetta (E.25), and Cynthia (E.24) all indicated that they had a support group formed by family or friends, and were therefore better able to handle their diagnosis. Shirley (E.27) suggested that she was helped because she could confide in her partner, who had also recently discovered that he was positive. His understanding and support helped her to cope with both their positive diagnoses and with their future. She gave a small laugh and said:

***"I don't believe that I could have coped without all his support; having said that it would be fair to say, neither could he have, without me!"***

A few women in Edinburgh, who discovered their diagnoses in the late 1990s, recalled how they were helped to explore all the options they could choose to take care of themselves and enable them to heal their bodies. These women were able to find and make use of resources and information that became available through a variety of sources. Julia (E.16) recalled how the information that was available on the Internet and the various books and articles that were available went a long way in battling some of her fears.

## **Anger & Resentment**

Anger was the chief or predominant emotion expressed by the majority of the women in the days and weeks that followed their diagnosis. For most women, once the shock and overwhelming feelings of sadness and pain had settled, anger surfaced to the forefront. Only one woman (Aarti, B.1) reported anger as her immediate reaction to

her HIV/AIDS diagnosis. She said that she felt rage bursting through her when she realised that her husband had been instrumental in the illness of their child. She said:

***“I have never felt such anger before, but knowing that his dirty deeds in the past had taken the life out of my bubbling child, I just felt mad, mad with so much rage.”***

She also spoke about her strong feelings of anger and resentment towards a nurse in the hospital ward where her daughter was being treated, because she kept referring to them as the ones with AIDS, and asked Aarti several personal and embarrassing questions about her husband’s past sexual history.

The words that women used to express their feelings of anger differed in the two contexts. While the majority of the women in Bombay spoke about their feelings of anger, they tended not to use the word for anger itself: *gussa* (in Hindi); *gusso* (in Gujarati); or *raag* (in Marathi). Instead they spoke more euphemistically and talked about crying, being very upset and miserable with God, their in-laws, their husbands, or with the way life had treated them. These remarks were accompanied by nonverbal cues, such as tone of voice and gestures, which suggested strong anger.

Four women in Bombay recalled being extremely upset with God for the pain that He had put on them. They seemed to direct their anger towards God, whom they perceived as an anthropomorphic being, up there, who was purposely meting out punishment to them. Kumud recalled how she went home and wept near the *mandir* (literally, means temple. Many Hindu families in India have a corner of the home that is converted into a holy corner, with pictures and idols of the different pantheon of Gods and Goddesses they worship, where they burn incense or light a lamp and do their daily prayers). She said:

***“I was so upset with him that I banged His picture and broke the glass. I cried and cried and asked him: How could you do this to us? How could you? I did not care, I was so upset that He did this”***

Aditi (B.2) recalled that she kept crying when she discovered she was HIV positive. She said that all she remembered was crying continuously for four days and fighting

with God in her mind. She recalled that later she was ashamed that because of her grief she had torn all the pictures of God.

The recollections of five women reflected feelings of anger towards their husband's families. These women directed their anger to their partner's families, rather than to their partners, who had in fact infected them. When I questioned them directly about whether they felt angry or upset with their partners, all of these women replied in the negative. They seemed to totally condone their partners' actions and displace their feelings of anger and resentment on their in-laws. When I tried to suggest that their partners had some role to play, most said that it was not their partner's fault. This seems to reflect their socialisation, which teaches them to totally overlook the sexual indiscretions of their partners, because they are men, and men have their needs that must be satisfied. It seems to be more socially acceptable to express bitterness, anger, and frustration towards in-laws rather than husbands. Savita (B.13) spoke very vehemently and plainly about the bitterness and hatred she felt towards her husband's family, when she realised that it was because of them that she was suffering. She defended her dead husband and said:

***"I was not upset with him for going out and doing things. He was a man; he needed it. He went out; what could he do. His mother is the devil. She wanted him to herself and that is why she did not get him married in time, and then brought this big problem on my husband and me. "***

Some of the Bombay women did feel anger towards their husbands when they discovered that they had infected them. These women verbalised feelings of betrayal, feeling let down, and being upset. However, for these women the anger seemed to be expressed more non-verbally. Nisha (B.8) clenched her fists several times when she recalled the betrayal she felt towards her dead husband for infecting her. Perhaps the fact that her husband was dead might be a reason for not openly saying that she was angry. She said:

***"I should not be feeling this way, because I do not want to disturb Sardaji's atma (her husband's soul), but I feel just so deceived ... what need did he have to do all this dirty work outside the home, when his children are so grown-up?"***

Meera (B.9) recalled feeling very sad and upset with her husband, when she realised that he had infected her and possibly their son. She used the word anger when I asked her if she felt angry with her husband, but hastened to add that she had totally forgiven him when she came back to her senses.

The accounts of Priya (B.14) and Prabha (B. 5) reflected deep feelings of antagonism towards the society they were born into as well as self-recrimination when they discovered they were positive. Priya spoke about all the pain that she had borne all her life, because she took birth into a low caste. She said that she was so bitter with her life for putting her in the position that she was in. When I tried to ask her what she was feeling at the time she was diagnosed, she spoke about hating herself for being in the position that she was in. She seemed to blame herself for the fact that she was born as a woman into a low class family, a circumstance that was really out of her control. She turned her anger on herself rather than direct it towards her husband who had infected her. Prabha (B. 5) echoed these feelings. She said that she felt contempt towards herself for letting her life get so badly ruined. She repeatedly said during the interview, that she was an educated person, who could read and write and wondered how her life had come to be the way it was. She said:

***“I wanted to hurt myself and that child who was growing in me. How did I allow myself to become a prostitute? Was I blind that I did not understand my aunt’s motives? Why did I not run away, when I could have?”***

Nine women in Edinburgh (out of 12) used the word “anger” very directly. Perhaps the differences can be attributed to the different ways in which women were socialised. Anger is generally thought of as a very negative, destructive emotion, and many of the Bombay women, who were brought up in more traditional, deprived backgrounds with limited education, internalised the feeling that anger was to be suppressed, even the word itself. Anger is a more socially acceptable emotion in western cultures, and sometimes it is even seen as a positive and therapeutic force.

Five women spoke about their reactions of anger towards their partners when they realised that they had been infected with a “life-changing illness” (Janetta’s words) by them. Like some of the women in Bombay, their feelings of hurt and upset and

betrayal were closely tied into their feelings of anger. Janetta and Susan recalled experiencing feelings of deep hurt and betrayal that their partners had not disclosed earlier relationships to them. Janetta nervously rolled the end of the tissue paper she was holding, repeatedly bit the side of her lower lip and had tears as she recalled the sheer frustration and anger she felt when she realised that her boyfriend had done “something like this” to her and “doomed” her in this way. Nonetheless, she seemed to condone her boyfriend’s behaviour and gave him the benefit of the doubt, for perhaps not knowing that he was positive.

Susan (E.27) recalled feeling terrible rage with her partner, both because she felt he had betrayed her and more importantly, because she was pregnant and was very frightened that their child would be affected. She said:

***“I went ballistic, I was so mad with him. I could have killed him. He always let me think that I was his first and only love. I think he’d done that to make me feel great and all that ... in that moment all my dreams for my baby were dashed ... I felt so destroyed, I could only think of hurting him.”***

Belinda (E.22) echoed Susan’s feelings of anger. She said that she found it too painful to imagine that her in the flash of a moment, her life’s dreams and hopes had been totally destroyed.

Marcia (E.26) and Cynthia (E.24) spoke about feelings that included deep disappointment, pain, and anger at the injustices they had experienced from their partners. While Marcia recalled feeling angry and very depressed with her husband for infecting her, she said that she just accepted it, because, “... he was just a no-gooder from day one.” Cynthia recalled that the anger she felt helped her for the first time to clearly see how unfairly her husband had treated her and how much she had put up with.

Andrea (E. 18) recollected that soon after she had been diagnosed, she began methadone treatment, and that’s when being positive really hit her. She recalled feeling incensed with the government for not preventing the HIV epidemic in Edinburgh. She emphatically suggested that, although the Government at the time

knew that HIV was being transmitted heterosexually and that drug users were at particular risk, they never did anything about it.

Wilma (E.20) and Allison (E. 23) both expressed feelings of anger towards themselves when they began to accept the reality of their diagnoses. Like Priya (B.14) and Prabha (B. 5), they said that they were very angry with themselves for allowing their lives to “touch rock bottom” (Wilma’s words). Moreover, Allison seemed to feel really infuriated not only with herself, but also with her life, which she seemed to personify. She recalled feeling really angry and desperate that she had got HIV, because despite the difficulties involved, she had gotten off drugs so that she could have children, whom she loved beyond all else. She said:

***“How could life have done that to me? He kenned that alls I ever wanted were bairns, and to give them all the love I could, because my mother was so sickly and I never got the love I wanted. I thought I could give it all to my bairns, so I cleaned up my act, but yet I got mysel’ in a fine mess”***

The reactions described above seem to fit well with the stage of anger described by Kubler-Ross (1969). Kubler-Ross refers to the second of her five stages as one of anger, characterized by feelings of rage, of wanting to strike out at God, a partner, the Church, or other people “who are not going through the same thing”. She also notes that this stage may include feelings of anger at oneself for having contributed to the loss (Kubler-Ross, 1969, 44-71). Speaking about her own personal experience of a life threatening illness and incapacitation, Kubler-Ross (1997a) notes that she only experienced the second stage, that of anger (Kubler-Ross, 1969). In the case of the women I studied, I observed that what Kubler-Ross describes as stages were more like fluctuating periods of human sensation or feelings, rather than clear steps or stages. Because they were expressions of feelings, they did not follow any kind of linear pattern. Moreover, the feelings seemed to fuse into one another and overlap at times as well.

Bowlby (1986) notes that disruption in important bonds of attachment and affection can lead to feelings of anger, and this seemed to be reflected in the accounts of some



of my participants. As noted earlier, many of these women had experienced the loss or devastating illness of loved ones, and they often seemed to be overwhelmed by their feelings associated with these losses. Key attachment bonds in their lives were disrupted or ripped apart by their circumstances, and this could have contributed to the strong feelings of anger that they expressed.

Finally, rage and anger seemed to provide a cathartic means of expression and of accepting HIV/AIDS in their lives. Thus, the expression of blaming God, their abusive families and relations, and the government helped to liberate these women. This ability to liberate themselves at this stage helped them to move from one state to another (Golan, 1981) and make a transition to new levels of adjustment to their situation.

## Conclusion

This chapter has focused on the diagnosis stage and the key issue of the impact of HIV/AIDS diagnosis. The main finding that has emerged from the women's accounts of their lives during this stage is that anger and resentment were the chief reactions to an HIV/AIDS diagnosis.

This chapter has focused on a somewhat narrow time frame confined to the time immediately surrounding diagnosis. The next chapter discusses the post-diagnosis stage, and explores the turning points, transitions and transformations that occurred as more time passed after diagnosis and the process of long-term adjustment began. It is important to emphasize that although the concepts of turning points and transitions are discussed in the next section on post-diagnosis, it does not in any way mean that these changes were only a part of the post- diagnosis period.

## CHAPTER 7: THE POST-DIAGNOSIS STAGE

### Introduction

This chapter discusses the post diagnosis stage in the lives of the women. This stage covers the time after the diagnosis up to the time when the women were interviewed. For majority of the women in Edinburgh this period spanned between 10 to 15 years, whereas for the majority of women in Bombay it spanned between 2 to 5 years. There were exceptions in both contexts: one woman in Bombay had only known about her diagnosis for the past year, and one woman in Edinburgh had only known for 3 months.

The key issue for the post-diagnosis stage concerns long-term adjustment. How do the women manage the many changes that come to their lives as a result of HIV infection, and how do they function over time? The concepts of turning points, transitions and transformation, discussed in Chapter 2, appeared to be most relevant here. These concepts describe different aspects of the change process, and change seems to be an inevitable reality for the women in my study.

This chapter is divided into four sections. In the first part, I focus on the concept of the turning point. I had expected that being diagnosed with HIV would be identified as a crucial turning point by the women in my study; however, their perceptions in this regard were often unexpected. Although a substantial minority (seven out of a total of 27 respondents) did describe diagnosis as the major turning point, the majority of the women did not. Hence the first assertion for this chapter notes that different experiences of loss were perceived as the major turning points for the majority of the women. These experiences occurred at various times during pre-diagnosis, diagnosis, and post-diagnosis, but the women uniformly reported that they were the key experiences around which the major upheavals of their lives were organised. These experiences of loss were perceived as the crucial events, even though all of the women acknowledged the tremendous impact that the diagnosis of HIV/AIDS had on them.

The second part of the chapter focuses on transitions and HIV/AIDS in the lives of the women. It focuses on the ways that HIV diagnosis contributed to their early efforts to change their lives. The second assertion for this stage notes that an HIV/AIDS diagnosis marked the beginning of a transition or a journey into something often unknown (Brammer 1991) in a majority of the women's lives.

In the third part of this chapter, I describe the transformations that occurred in the lives of my respondents as a result of their experience of living with HIV/AIDS. I asked the women to share with me how being positive had affected or changed the way they felt about important aspects of their lives: love, their life, religion or faith, pain and loss, and death. I also asked them whether the experience of living with HIV/AIDS had helped them to grow, or develop inner strengths and potentials that they may or may not have known they possessed. This leads to the third assertion for this stage, that HIV/AIDS transformed the women's lives by affecting many crucial aspects of their person and changing who they were, possibly because it altered or destroyed so much that the women had previously accepted as normal.

The last section focuses on the phenomena of acceptance and hope in the post-diagnosis stage. Although many of my respondents experienced great tragedy and deprivation, they found ways to deal with their situations and to find new meaning and hope. The last assertion for this chapter reflects this finding, asserting that the respondents experienced acceptance of the reality of their life situation and the capacity to hold hopes for their future.

### **The Nature of the Turning Point: Loss versus HIV/AIDS Diagnosis**

The majority of the women in my study identified various experiences of loss, which they had lived through both before and after they received their positive diagnosis, as a turning point in their lives. Twenty out of the twenty-seven women focused on these experiences of loss, which varied from actual loss of a loved one, to betrayal, to disappointment, to loss of innocence and femininity, to loss of a future and children, and loss of sexuality. Although all of the women looked upon the experience of

HIV/AIDS diagnosis as important, only seven described the diagnosis as the key event that led to changes in their lives.

For many of the women, the loss was a literal one. Fifteen women described the loss of a partner, child or family member, recalling that their lives were never the same after these losses. For most of these women, the loss was connected in time to their own diagnosis, as they lost spouse or children to HIV/AIDS and also discovered that they had contracted the disease themselves within a short time frame.

Seven women in Bombay spoke about the death of their husband (or fiancé, in the case of Parul (B.4) as a major turning point in their lives. For women in their culture, the loss of a husband is particularly devastating. In traditional Indian society the status of a woman is dependent on her husband, and being a widow makes her almost a non-entity. Leela (B.6) explained that being a widow in her caste meant that she would have to live a life of isolation and rejection. Nisha (B.8) recalled the prevailing superstitions that existed in relation to widows in India. Savita (B.13) sobbed as she recalled how although she was totally innocent, she was a social pariah, because she was a widow, an ill-auspicious omen.

For Leela, the loss was symbolised by the removal of the vermilion powder, the red dot that Hindu married women put on their foreheads and in the centre parting of their hair, as signs of “soubhagya” (literally meaning good fortune in Sanskrit) or of being married. Rashida (B.12) who wore a hijab (the dress of Muslim women, which covers them completely) also spoke about symbolic losses associated with widowhood. However, it was not the loss of her husband but the loss of her youth and femininity that changed her life. She recalled how her in-laws had stripped her of all the jewellery her parents had gone into years of debt to buy for her at her marriage. She said:

***“When my husband was alive they made me into an untouchable, but now that he is gone they are nicely wearing my jewellery. That is not dirty; that is not untouchable ... I am young, I should be able to wear all my things. I cannot bear to see my naked hands, not even one bangle, everything bare ... they have taken away my years and made me old”***

Savita (B.13) and Nisha (B.8) also talked about the loss of financial support, which they experienced after the death of their spouses, as the turning point in their lives. Being without any money or being in debt, as Nisha was, changed their lives completely. Savita recalled that she was forced to go back to and live with her family, because her in-laws refused to keep her after her husband's body was cremated.

Some of these women, especially the more educated in the group, spoke about emotional loss as well as the loss of their role. Namita (B.3), Meera (B.9), and Parul (B.4) talked about how losing the man they loved so much changed their lives. All three women spoke rather candidly about the love they had shared with these men. Namita and Meera also talked about the loss of person whom they depended on and believed would protect them. These women had been socialized from girlhood to depend on men: first, their fathers, then their husbands, and finally their brothers or sons. Since her widowhood, Namita was cared for by her brother, and Meera depended on her husband's brother.

Parul, still a teenager when I spoke to her, used many superlatives to explain how much in love she and her fiancé had been. HIV/AIDS brings particularly poignant loss to women like Parul, who are only just beginning their lives. In her almost childlike, magical consciousness, she idolised this man to whom she was engaged. They were teenagers in love, and she could see no wrong in him. The fact that he died so tragically, before they could really live and experience life together, ensured that he would remain a hero in her mind. She used words like "over the moon" and "floating in the sky" to describe her feelings for him. She recalled how she spent her day dreaming of their meeting in the evenings and her afternoons "dressing up prettily" with flowers in her hair.

Leela (B.6) also spoke very poignantly about her loss. She had been an orphan from a young age and had always craved for love. She said:

***"We were both orphans and we wanted just so much to love each other. When he died, I felt as though me and my son were left as orphans again...I was so scared to be alone again; after he went my life changed completely."***

Finally Kumud (B.7) said that the losing her child and her husband, both on the same day, was a thousand times more painful than her burns accident. She said that the accident had changed her life completely at the time, but that once she had recovered it was over for her. But the loss of her child and the loss of her husband were a loss she would never recover from, and they had changed her and her children's lives forever. What she had to say and the way she said it were very poignant:

***“See when I got burnt, I could not smile, because this side was very tight; it pulled very badly. My husband would tell me smile with your eyes; I can see you smiling ... but now that they are gone, my face has started to smile, but my eyes can never smile again, they can only cry.”***

Although all these women spoke about the loss of a partner as a turning point in their lives, the way they perceived loss was very different. For some, it was the loss of the love of their lives, for others it was the loss of economic stability, for others it was loss of social status, and for yet others it was a combination of these.

Leela (B.6) and Cynthia (E.24) described the loss of their children as a major turning point in their lives. Leela said that her own HIV diagnosis was insignificant in relation to the loss she experienced when she heard that her “beautiful, doll-like son” was stillborn. She said that her life could never be the same after she had carried her stillborn son in her arms, and the doctors had pulled it away from her chest. Cynthia recalled that the death of her baby daughter to an illness changed her life completely. She said that the deep grief and loss that she felt has always coloured everything in her life.

Jasmine (E. 17) said that the attack in which she had been raped turned her life around completely, but the turning point in her life was the loss she experienced when the court gave her mother the custody of her child, because she had HIV and was believed to be an unfit mother.



Champa (B. 10) described the loss of her widowed, destitute mother, the only relative she had ever known, as the event that changed her life completely. She spoke about the harsh reality of her life in a rather child like manner. She said:

***“When she went to sleep that was it, I became all alone, all, all alone ... there is no one now for me on this earth of my own.”***

Urmi (B.11) and Aarti (B.1) described loss associated with the illness of their child. For both of them, worries for their own health were overshadowed by their immediate concerns in caring for family members who were already ill. They said that the seriousness of the illness of their loved one and the fear that they would die changed their lives. Urmi and Aarti both said that they cared very little indeed about their own HIV diagnoses.

Urmi's daughter had died a short while before the interview, and she said that now that her child had “gone away”, even life itself was insignificant, and it did not matter what changed her life. She seemed unable to understand what I was asking her, when I asked her whether knowing she was positive had changed her life, or whether anything else had. Throughout the interview, every question seemed to be answered in this vein, a mixture of fatalism and perhaps numbness.

Marcia (E. 26) and Andrea (E.18) described how the death of a sibling had changed their lives irrevocably. Marcia spoke about how her life fell apart when her brother was murdered. She recalled that his departure “changed everything” in her life, because, although he was a few years her junior, he had always been her pillar of strength and support, and she had cared very deeply for him. Andrea spoke about the loss of her sister. She recalled that the HIV diagnosis had been a crucial point in her life because it had helped her get off heroin and onto methadone, which meant that she was away from heroin dealing and sex work. Although these were big changes in her life, they never really changed her life. She recalled feeling isolated and believing that she was soon going to die of AIDS. It was the death of her sister and the deep sense of loss that went with it that changed her life completely.

Julia (E. 16) and Janetta (E. 25) described the betrayal and disappearance of a partner, in each case someone they believed would be their partner for life, as the loss that they perceived changed their lives completely. Janetta said that because she did not have any answers as to what really happened to her partner, she felt as if she was stuck in her life, not knowing what to do.

For Champa (B.10), Priya (B.14), Rashida (B.12), and Lakshmi (B.15) the loss that they described as a turning point involved the loss of innocence, safety, and freedom that occurred when they entered into marriage. These four women experienced tremendous abuse and violence in their marriages, practically from the first day that they were married. All these women univocally pointed out that their lives changed completely after they were married to men who were several years their seniors. These women spoke about the loss of their maidenhood and the beginning of their married lives of abuse as a turning point. As Champa said:

***“The day I married my life changed forever; that was the beginning of all my real pain.”***

Priya (B. 14) and Lakshmi (B.15) voiced similar feelings, but spoke with greater force and vehemence than Champa (B.10) when I asked them whether they thought that receiving an HIV/AIDS diagnosis had been a point after which their lives would never be the same. Priya gave a bitter laugh when I asked her this. She said that after all the injustices that she had experienced at the hands of her in-laws; the diagnosis seemed irrelevant, almost as if it never touched her. Lakshmi said that the pain and humiliations she had borne since the day she married changed her life forever. She described herself as feeling numb as a result of the abuse.

Prabha (B. 5) described a different kind of loss as a turning point in her life. She spoke about the experience of “losing her life”, the experience of being sold into prostitution. She said that although she had experienced many problems and upheavals throughout her growing years, (a father who was an alcoholic and had sexually abused her sister, and a husband who was an alcoholic and very violent towards her) she said that her life changed forever when she actually realised that she

had been sold by her aunt into a brothel, where she would be expected to have sex with unknown men and live the life of a prostitute.

Only nine women identified an HIV/AIDS diagnosis as the key turning point in their lives. Wilma (E.20), Susan (E. 19), Molly (E. 21), Belinda (E.22), Allison (E.23), Shirley (E.27), and Julia (E.16) all said that their HIV/AIDS diagnosis had changed their lives irrevocably. Wilma and Molly recalled how their positive diagnosis led to a change in lifestyle and gave them the ability to stop using drugs (and to cease sex work in the case of Wilma). Molly recalled how it had made her sit up and think about her life, and what she really wanted from it. She added that the subsequent losses of her husband, her brother, and her sister-in-law had all deeply changed her life and what she did with it, but that her own diagnosis was the point that turned her life around.

Susan (E. 19) and Belinda spoke about how the HIV diagnosis completely reordered the priorities in their lives. Susan who was asymptomatic, said that she had never been affected by the virus, but she felt that diagnosis was a turning point because she turned her life around, spending more time with her son and changing her lifestyle of socialising, drinking, etc. She noted a change in her attitude and perspective. She said:

***“Being positive made me live life in a fuller way and do the things that were important to me. I was more involved in living life in the fullest way, without having the threat of HIV in my mind.”***

Jasmine (E.17) and Allison (E.23) focused on the devastating fear and sadness they felt when they realized they were HIV positive. Jasmine said:

***“Yes, my whole life changed. I was depressed; I was out of my mind. I felt I had lost everything. My son was taken away from me. I just existed. I don’t know; it was all a haze. Looking back I can only remember pain.”***

Belinda (E.22) said that learning that she had a fatal, terminal illness at the age of sixteen, at a time when little was known about HIV and AIDS, was a complete turning point, during which she lost all hope. However, after the “initial horrible six

months” she began to live well and to care for herself, and pointed to that as another major turning point in her life.

Allison said that finding out that she was positive when she was pregnant was the worse thing that could happen to her, and changed her life at the time of her diagnosis. She also spoke of the death of the brother she loved so well to AIDS and the sudden death of the father of her children a few months before the interview as other turning points in her life. Allison’s comment highlights another observation. For so many of the women, the HIV diagnosis was inextricably tied to other experiences, particularly losses. It was difficult for them to isolate either event as the turning point in their lives, because they saw the events as very closely connected.

It is interesting to note that the women who focused on the diagnosis itself as the turning point seemed to be relatively better off than many of the other respondents. They were not focused on the daily need to survive, and perhaps they could put their energy into taking care of themselves and thinking about their lives in a different way.

Regardless of the particular event that each woman perceived as her personal turning point, each woman was faced with the necessity of making changes and adjusting to a new reality after that turning point. The next section discusses the women’s perceptions as they began to deal with that reality.

## The Beginnings of Transition

Many changes occurred in the lives of the women as a result of their diagnoses with HIV/AIDS. I asked women to tell me about how HIV/AIDS affected them physically, socially, emotionally, and sexually, and affected their family life as well during this stage. Immediately after diagnosis, most of the women had experienced shock and confusion, but as time passed, they began the process of transition into new ways of living. Most of the early changes that signalled the beginning of

transition had to do with physical health. These early changes became elements of a transition that ultimately led to a new kind of existence for many of the women.

Transitions occurred at different stages for different women. For example, one woman in Bombay (Champa, B.10) pointed out that her life began to take a new direction during the pre-diagnosis stage, when her partner was diagnosed with AIDS and she was thrown out of his home, making her destitute. In another example, one woman in Edinburgh (Allison, E.23) described the death of her partner during the post-diagnosis stage as the beginning of a new life direction.

Perhaps the most immediate way to respond to a diagnosis of HIV/AIDS is in the area of physical care. One of the positive developments that occurred for a number of women in my study was a new sensitivity to their bodily needs. The accounts of Andrea (E.18), Wilma (E.20), and Allison (E.23) revealed that they had neglected their health while engaging in drug abuse. They recalled how receiving a positive diagnosis was the beginning of paying attention to issues they had previously ignored, such as nutrition, obtaining medical care, and taking care of their physical and emotional needs. Several women in Bombay who had ignored their health while coping with a plethora of more immediate survival concerns, also indicated that they began to pay attention to their bodies and to try to take better care of themselves.

For many of the women in my study, nutrition became a larger concern. While many of the poor women in Bombay had already been facing a constant struggle to avoid starvation, the advent of HIV in their lives meant that nutrition was even more important.

Savita (B.13) recalled how she tried to eat fruits, vegetables, meat, and fish as instructed by her doctor. Parul (B.4) too recalled how she had become very conscious of her health, and tried to sleep well and exercise and eat healthy foods as directed by her doctor.

For Jasmine (E.17), the diagnosis led, after a time, to a new concern with wellness and healing. She remarked:

***“I started doing things for myself, massages, therapies, you name it, I went for it... I went to many different healers; I went for spiritual soul healing.”***

Combination therapy was another new experience that entered the lives of the women in my study, albeit only those in Edinburgh. Anti-retroviral therapy is a complex regimen that requires strict adherence to a schedule for taking a number of medications. The advent of combination therapy into the lives of the women meant that they had to make changes in their lives in order to accommodate the regimen. Andrea (E.18) described the changes she had to make on account of the combination regime:

***“I was taking 18 tablets a day. I felt I was taking them all through the day...The regime was too much for me to take...You couldn’t do this and you couldn’t that. Side effects, diarrhoeas, if I scratched my head it was sore and hurt...”***

Cynthia (E.24) and Wilma (E.20) echoed Andrea. Cynthia wondered whether all the changes she had to make in her life were worth it.

Combination therapy was perceived as a double-edged sword for many of these women. While it provided hope and health for some, for others, as illustrated above, it was a bag of mixed blessings. Julia’s (E.16) account clearly reveals the dilemma women face in relation to combination therapy. She said that she felt under quite a lot of pressure from the medical establishment and the doctors in the hospital, although they were very nice and she had a lot of respect for them. She felt that because a lot was still unknown about combination therapy and its effects, it made it harder for her to make a reasonable decision.

Combination therapy also meant a new element of hope for the women in Edinburgh. They could not be certain how long they would be spared the ravages of AIDS, but they did have the new hope of living indefinitely, despite their status as HIV positive women. This required a shift in thinking about HIV/AIDS. They had to change their



outlook, from that of persons waiting to die to that of persons learning to live with HIV.

## **From Devastation to Transformation**

The accounts of the women revealed that the interplay of HIV/AIDS and the different complexities in their lives brought about radical changes in the lives of the majority of the women. Women in both contexts experienced negative changes; however, several women, mainly from the Scottish context, spoke about the positive changes that came about in their behaviour, values, attitudes, way of living, and their perception of life. These changes helped them to grow, to realise hitherto untouched potential, and to live more fully in the present, with a fresh appreciation of life. They were able to move beyond the pain and vulnerability they had experienced and engage in life affirming actions, reaching out to others and enhancing both their own lives and those around them. The nexus between their diagnoses with a life threatening illness, social support, care and human worth, and dignity seemed to be the catalyst for positive transformations in this stage. Being diagnosed with a life-threatening illness opened new vistas for self-awareness and realisation of inner potential.

### **Growth of Awareness and Mindfulness**

The accounts of those women who were able to make positive transformations suggested that being diagnosed positive and living with HIV/AIDS had caused them to be more mindful about their lives. The accounts of Parul (B.4), Belinda (E.22), Julia (E.16), and Shirley (E.27) revealed how being positive had made given them the opportunity to take care of themselves and give importance to their own lives. Both Parul and Belinda recalled that being positive had forced them to grow up and think about their lives. Belinda (E.22) said that it helped her to put herself “number one” in her life.

Several women in Bombay recalled how being positive had made them think about their own well being, something that they had never had the chance of doing before. Rashida (B.12) said very emphatically that she had never given any thought to life, and had moved with the flow of life, taking whatever each day brought. She said that she never knew what it was to think about life and what way it was going:

***“I felt sad when it was time to feel sad and cried, I felt happy when it was time to feel happy and I laughed, but when I got HIV myself, I began to think about my own life. If I did not no one else would.”***

For some women, being positive gave them a chance to stop and try and evaluate where their lives were going. Their accounts reflected how instead of the raw, almost mindless struggle for survival, they begin to think about what they are doing and how they are living. Priya (B.14) pointed out that she had started to take care of herself and spend time with her daughters, something that she would never have done if she were not positive. Marcia (E.26) and Shirley (E.27) also believed that being positive had made them stop and rethink what was most important in their lives. They both said that they now concentrated on their children. Shirley said that she was a full-time mum, who gave quality time to her child, because she knew “just how easily things could’ve been different”.

Contracting HIV enabled Prabha (B.5), Andrea (E.18), and Wilma (E.20), women who were marginalized and stigmatised, to think about their lives and to put them into a new perspective. Prabha said that having AIDS and being so close to death’s door gave her the chance to look back on her life and try and understand where it had all gone so wrong. But, she said, thinking made her “cry so much” that her head would hurt and she had once even fainted and fallen to the ground. Her traumatic experiences and her struggle with AIDS raised her consciousness beyond a simple focus on day-to-day survival.

### **Rethinking fundamental issues**

The accounts of a large majority of the women revealed that being positive made them look at fundamental issues such as love, life, faith, pain and loss, and death

very differently, such that it transformed their lives. The experience helped many of them to find their innate potential and strength, which they had not known until then.

The psychological consequences of HIV were very profound for the women I studied, because they are indirectly connected to their role in life (Sherr 1991). This part of the interview demonstrated that most of the women had a deep understanding of the complexities of their lives. This was true even for women with little education, and for women who had experienced severe loss and trauma. These women were able to express the idea that having HIV/AIDS had transformed the way they thought about some of the deeper aspects of their existence.

**Love.** When I asked women about how being positive had affected the aspect of love in their lives, women in both contexts spoke very honestly. They all believed that it had affected the way they felt about love. While most of the women spoke about the about the notion of romantic love, the majority of the women who had children focussed their discussion on the children. Leela (B.6), Shirley (E.27) and Cynthia (E.24) spoke about both aspects of love. There was only one exception, Champa (B.10), who spoke about her love for her mother.

Leela mentioned the intense love that a man and woman share and noted that being positive only made this love between the two of them very strong. Shirley reflected similar feelings. She said that she and her partner had become much closer and more deeply in love after all the pain and distress of realising that they were positive had been accepted. She said:

***“Love is about forgivin’ and forgettin’, about loyalty, and stickin’ by your man... it’s about givin’ all you’ve got to the wee, beautiful bairn that’s both of ours.”***

The accounts of many of the women expressed how becoming positive had affected the aspect of romantic love in their lives. Some of the women in Edinburgh said that being positive made relationships more complicated, because of the dilemma of revealing their positive status. Cynthia (E.24) said that she found the aspect of negotiating protection very difficult. She recalled that her last boy friend had refused

to use any protection, although he knew about her positive status, which made her suspicious about his status and terribly guilty at the same time.

Rashida (B.12) noted that even before her own diagnosis her husband was ill all the time. She said that she found all “his love business” extremely cumbersome. Although she was only 21 years old at the time of the interview, Rashida already conveyed a sense of world-weariness. She had been widowed at a very young age, and now she faced the ravages of HIV infection. Life had disenchanted her so quickly. Wilma (E.20) spoke about love in a similar disillusioned manner. She said that she had had enough and at the end of the day, it was only God who could really love.

But the opposite was true of other women. Shirley (E.27) and Belinda (E.22) said that being positive made them love more intensely, because it was a gift. Shirley said:

***“We are both positive, guess that makes it that wee bit easier, but I think it’s more the pain we’ve been through that makes us so close. And the fact that our baby’s been saved from being positive strengthens our bond.”***

Belinda (E.22), on the other hand, said that because she and her partner were sero-discordant, their love was very strong. She echoed Shirley about the bond between her and her partner being stronger because their child was not positive.

Meera’s (B.9) account revealed what other women like Aditi (B.2), Namita (B.3), Leela (B.6) and Savita (B.13) all alluded during the course of our interviews: the lack of privacy available to a husband and wife in the context of low-income accommodations. She recalled rather movingly how she and her husband longed to spend a few moments alone, but were never given the chance. She said:

***“We were never able to be close physically because he was so ill, but all we wanted was to hold my hand. But someone or the other would be around. We would really long to be close just for a few minutes, but it never happened ... I wanted so badly to be alone to just hold each other and cry.”***

Namita (B.3), Parul (B.4) and Savita (B.13) believed that HIV/AIDS cut short this beautiful aspect of love in their lives. Savita remarked that love had “just been cancelled” for her.

Namita, Janetta (E.25), and Parul all said that they missed their partners terribly. Janetta said that she missed him especially on her birthday, their anniversary and Christmas, when other girls were going out with their boyfriends. Namita said that her husband had always been so gentle with her, that she found it easy to forgive him for being unfaithful. Parul talked about love in clichés of the sky, the moon and the stars.

Julia (E.16) spoke about the intense love she had shared with her boy friend, and how his betrayal had left her feeling almost asexual. She was frightened about how being positive would affect her sexuality. However, she had recently met a friend, with whom she had been intimate in the past, and told him about being positive. She said that he had held her and made her feel desirable, and that the experience had been “revitalizing and reassuring.” She also spoke at some length about how being positive had demonstrated the true friendship bonds that existed between her and some of her girl friends, who had supported her and literally seen her through many arduous points since then. She said:

*“Being positive has sharpened all my feelings, because it has put things into such a clear perspective. It has also brought my friendships to deeper level, where I and indeed friends too are able to really communicate, because we all have different problems in our lives. I may be positive, but they’ve got other problems, so it’s all about reaching out.”*

When asked to relate her experiences with love, Andrea (E.18) talked about another kind of love—the humanity of a stranger, which she referred to as love. The day she received her diagnosis was her 30<sup>th</sup> birthday, and she had been hastily told that she would be shifted into another hospital for people with contagious diseases. She recalled how a doctor had come and asked her to take her time and think about whom she wanted to share her diagnosis with. The doctor’s simple act of humanity and his willingness to touch her, at a time when fear of contagion was at its peak, seemed like an act of love to Andrea. This also points to a concept that will be discussed

further in chapter 8, the value of human compassion and dignity in bringing about transformation.

Cynthia (E.24) spoke about the complexities that HIV brought into her sex life. She said that she preferred being celibate because of all the problems involved in relation to infecting another. It made her feel very lonely at times. She said:

***“HIV has changed the way I express myself sexually, and I do not like that. I do not have many relationships because of the HIV, because I would not pick a partner who did not have the virus, because I would be too scared to give it to him ...”***

All the women who had children spoke about how being positive increased the intensity of their love for their children. It made them realise how precious their time together was, and they tried to spend as much time as they could with their children. It also made them more demonstrative. Jasmine (E.17) said that a day never passed by when she did not tell her son how much she loved him. Nisha (B.8) said that after she became positive she sometimes hugged her teenage children with affection, like when they were children. This is not something that would normally be done by people from her cultural background.

Allison (E.23) also spoke with great pride and affection about her children and the depth of her maternal love.

The element of deep love and the impending pain of loss were evident in the accounts of Aarti (B.1), Prabha (B.5), Leela (B.6), Meera (B.9) and Kumud (B.7), who all spoke about the wrenching process that being positive had brought to them as mothers. They feared that they were either going to see their children die, or even worse, leave their children without anyone to care for them.

In general, it appeared that being positive brought awareness about the fragility and impermanence of life, which transformed the women's relationships. Some accounts reflect how HIV helped to move their affection and love with their partners to a



deeper level. For the same reason perhaps, the women's love for their children became more unconditional.

**Life.** Aditi (B.2), Namita (B.3), Parul (B.4), and Julia (E.16) said that being positive forced them to accept the fact that they might never have the chance of experiencing the most basic of female experiences: giving birth to a child. Julia (E.16) said that she found it difficult to reconcile to this fact. She said that she associated pregnancy and giving birth to a child as part of a successful woman's role, and being positive had changed her life's path forever. She recalled too the regret that she felt because she had terminated her earlier pregnancies, several years ago, because her husband had not been too keen to continue with them.

Aditi (B.2) and Namita (B.3) believed that being positive had changed the way they looked at themselves, because they could not have a child. They spoke about being barren and highlighted how not being able to have a child left them with a wide gap in their lives. Bearing a child is very much a socially valued option for poor women in India. Aditi's explanation was rather poignant. She used the metaphor of a road to explain that marriage and childbirth were like a straight road, on which HIV appears as a sudden block. She said:

*"And then you fall, you could fall this side or that side, no one knows, but your journey is broken."*

**Religion and faith.** The accounts of a large majority of the women reflect the idea that being positive changed the way they looked at religion or faith. The women used various words to describe this aspect of their lives: God, faith, religion, and "something higher". There were three different ways in which women said this aspect had been transformed. Some said that they had religious faith previously, but they were so angry initially that they could not feel much faith. Over time these women realised that their faith had increased. Other women said that they did not believe initially, but the transformation was that they began to believe. And finally there were those who always believed and who began to believe even more.

The accounts of Aarti (B.1), Aditi (B.2), Parul (B.4), Prabha (B.5), Kumud (B.7), Savita (B.13), Marcia (E.26), and Shirley (E.27) revealed deep feelings of hurt, anger and frustration that were directed to God when they began to react to the reality of HIV and traumatic losses in their lives. It is interesting however, that all these women, with no exceptions, spoke about how being positive had eventually renewed their faith. Parul (B.4) recalled the dramatic shift that she had experienced when her fiancé died. She recalled how she had always been a great believer in God, and had been deeply religious praying, fasting and going to the temple etc. She said:

***“When he was placed on the pyre I screamed out in anger...I hated God, because I thought he had let me down. But now I have come back to my senses. Who am I not to forgive God? I pray daily and touch the feet of God and beg for forgiveness, for any mistakes or sins that I have done. ”***

Aarti (B.1) recalled how the terror of her child’s diagnosis, followed by the news of her own and her husband’s diagnoses had shaken her belief in God. She said that she had gone mad at the time because of the fear, but that now she did not blame God. Marcia (E.26) spoke about how the deep hurt she had experienced had made her question her faith and wonder whether there was anything like a God. She said that she had felt let down by Him. She spoke about how with time passing and an acceptance of what life had brought to her, her faith had become much stronger. She said that although she was not sure about who, where, and what God was, she believed in something, and that being positive and living well with HIV had definitely made her faith stronger.

The accounts of the majority of the large majority of women (18, out of 27) from both contexts revealed that becoming positive had transformed their faith and made it even deeper. The accounts of Namita (B.3), Leela (B.6), Nisha (B.8) Meera (B.9), Urmi (B.11), Priya (B.14), and Lakshmi (B.15) revealed that they had become more ritualistic, that they observed more regimes of fasting and prayers. They described the change as becoming more deeply religious and believing or loving God more. Jasmine, Wilma, and Andrea also reiterated that being positive had deepened their faith in God. Andrea said:

***“...I have always believed that God was looking after me and watching me. He had a lot of looking after, with all that I have done. I should have been***

***dead long ago, but I am sitting here and talking to you. I don't know what he is saving up for me, and why he's protecting me. But I firmly believe that I will be forgiven for all my sins."***

Finally, Nisha's (B.8) account reflects how being positive transformed her faith. She recalled that she did not really believe in religion; however, becoming positive had made her believe in prayers and God. She said that when she was in so much pain, the only person she could call out to was God. She said:

***"For the first time in my life, I really pray and go to the Gurdwara with my heart fixed on God. Earlier I only went; because I was forced ... I was not sure whether God existed, but now I know He does."***

**Pain, Loss, and Death.** When I asked women whether being positive had changed the way they looked at the aspects of pain, loss and death in their lives, I was surprised at the consistency of their responses. The overwhelming majority (23 out of 27) said that the pain and loss they had experienced had made them better people. They cited common reasons for this: the capacity to bear more pain, a new sense of patience, heightened compassion, an understanding of the pain of other people, and an ability to live in the present. Andrea's words epitomise what the women in both contexts understood:

***"I have learnt to be a stronger person, a more positive person. It has made me learn to appreciate life more, to have a better attitude, to enjoy life as much as I can, and to reach out to others who need the help".***

All of these women saw the experience of pain and loss as an avenue toward growth. Perhaps this idea helped them to accept their pain and to find some sort of meaning and purpose in their suffering.

The women in Bombay and Edinburgh in general spoke very briefly about death. According to the overwhelming majority (26 of the 27) being positive had transformed the way they felt about death. The exception was Janetta (E.25), who said that she did not want to talk about something as depressing as death. Julia (E.16) said that the main change that being positive had made was to compel her to think about her own mortality.

Several women (for example, Savita (B.13), Meera (B.9), Namita (B.3), Andrea (E.18), and Marcia (E.26)) said seeing death first hand had taken away their fear of dying. Several others (for example, Andrea (E.18), Wilma (E.20), Molly (E.21), Belinda (E.22), Allison (E.23), and Marcia (E.26)) said that they believed being positive and seeing so many of their friends and lovers dying of AIDS had transformed the way they saw their own death and mortality. They no longer feared it, because they believed that they were saved for some important reason. It is interesting that some of these women viewed their survival almost as redemption.

On the other hand, Savita (B.13) pointed out that she was terrified of sickness and a lingering death, after having seen her husband's painful death from AIDS. Andrea also expressed concern about facing pain. She said she saw death as an escape from the pains of HIV and AIDS. She said that if she were in a lot of pain, she would take an overdose and die. Several women in both contexts expressed a hope that they would die peacefully without suffering. Some of these women had nursed their very sick partners with AIDS and had been a part of the day-to-day suffering and deterioration of their health.

Finally, all sixteen women who had children, with no exceptions, expressed the deep hope and need to remain alive for their children. The majority of the women said that they wanted to live until their children were independent and able to support themselves. Some of those women whose children were adults, or some of those women whose children were adults and had children of their own, such as Cynthia (E.24), wanted to live to see the grandchildren get a little older. These women expressed the changing hope in the lives of positive persons with regard to their children. First they hoped to live until their children could take care of their own needs; then they wished to live until the children were mature enough to understand life; then until their 16<sup>th</sup> birthday and then their 18<sup>th</sup> birthday, and so on. As each milestone was passed, hopes for reaching a new milestone began. Molly (E.21), who had just celebrated her child's eighteenth birthday, recalled how she had always hoped she would live until this important milestone, although she had not dared to think that the hope would become a reality.



Parul (B.4) spoke about not wanting to die because of her mother. She said that she was ready to die as soon as God wanted her, because she knew that she would be reunited with her beloved fiancé; however, she could not bear to think of the pain it would cause her mother. For this reason, she was doing her level best to take care of herself and stay well.

### **Finding inner strength**

An overwhelming majority of the women (25 out of 27) observed that being positive had enabled them to draw strength from within themselves, which in turn gave them patience and courage to face HIV/AIDS in their lives. This observation was prevalent among women from both contexts, including some women who were coping with very difficult situations. Aditi's (B.2) words embody the responses of women in both contexts:

***"I have developed a capacity to bear things. This strength has come from my grief and pain. I have the courage now to bear pain and bad news and keep it inside me. I have not hurt my family by telling them. I could easily tell them, my mind would be so much more at peace. But what about them? I get a lot of strength from the thought that I am protecting them. It makes me feel very strong."***

The two exceptions were Urmi (B.11) and Janetta (E.25), both of whom had been unable to make any positive changes in their lives. When I asked Urmi whether she felt that HIV had helped her to develop an inner strength or potential that she did not know she possessed, she was very matter of fact in saying that it had not:

***"I think I was very strong even before HIV. HIV has not really made me stronger, it has only made me sadder, but I was strong from the very beginning."***

While Urmi spoke about developing sadness rather than inner strength, Janetta spoke about developing mixed feelings towards her life. She described herself as confused and exhausted.

Many of the women who did report finding inner strength were able to think differently about the meaning of their lives and to find ways to give to others. The next section discusses these developments.

### **Finding meaning and the ability to reach out to others**

The accounts of several women reflected how being HIV positive helped them to find meaning in their own lives, because it helped them to reach out to others. Myers (2000) argues that the skill of finding positive meaning when facing great adversity is closely related to how well people cope with crises, and the accounts of these women exemplify this idea.

Molly's (E.21) account highlights how she transformed herself out of her own need to be heard and understood by professionals. She recalled how she felt that she did not receive the respect and dignity that she so strongly hoped for, and this motivated her to take the leadership in managing an organisation for positive persons in Edinburgh. She said:

***"I am able to talk and discuss and fight on the behalf of other positive people; I am a changed person. Being positive has made me truly understand and listen to what other positive people are saying."***

Allison (E.23) said that being positive had helped her to reach out to people more genuinely. She said:

***"It's made me more understanding, loving, and forgiving, so people feel good with me."***

Leela (B.6) spoke about her involvement in a woman's group in Bombay, and how she had been able to support positive women. She said that if I had asked her three years ago to speak in front of a group of 30 people, she would have died of embarrassment. She said that now she speaks out, because she wants to help other women learn to fight back against HIV by taking care of themselves.



## Overcoming Drug Abuse and Dependence

The accounts of four women from Edinburgh reflect how becoming positive was transformational because it enabled them to overcome their lifestyle of drug use and dependence. In the case of Andrea (E.18) and Wilma (E.20) the transformation seemed more dramatic, because it also enabled them to break free of the sex work that they had been forced into in order to support the drug habit.

Andrea said that when she looked back on her life, she felt it had been worthless and very miserable. She used rather strong abusive language to express her feelings about herself as a person who used drugs and was forced to prostitute herself to survive. She said that being able to conquer the drugs had changed her life completely, and made her feel truly alive.

Wilma (E.20) and Molly (E.21) said that being positive had helped them to break away from their drug use because it had helped them to truly appreciate the time they thought they had remaining. Wilma (E.20) said that it was as though a dark curtain that had clouded her sight was lifted. She said:

***"It struck me right here (thumping her chest) stronger than ten burly men ... what was I doin'. I needed to do something in my last few days; I could not allow that precious time to be wasted ... it really made me pull my act together."***

Allison (E.23) spoke about her deep joy at becoming pregnant and the realisation of being positive that was coupled with it. She believed that both these events had compelled her to break her deadly habit, and freedom from the habit was life giving.

## Negative Transformations: Grief, Isolation, and Worry

Positive transformations did not happen for all the women, however. For some women in Bombay, thinking about their own lives was a luxury that they, whose lives were so fraught with adversity, could not afford. One of the women in Edinburgh (Janetta, E.25) also experienced negative transformation. In Janetta's case, the loss of her boyfriend along with the blow of the HIV diagnosis had been too

difficult for her to deal with. The transformations that these women emphasized were negative changes, which in fact did not enable them to live life fully or move beyond their sorrow and pain and engage in life affirming actions (Tatelbaum 1981). Another factor that some of these women seemed to share was unresolved grief. Janetta (E.25) recalled how the pain and hurt she felt had changed her life for the worse permanently. While the resolution of grief can be life giving (Krantzler 1973), unresolved grief makes individuals vulnerable.

The accounts of Aarti (B.1), Prabha (B.5), and Kumud (B. 7) reflect the anguish and complexity that HIV/AIDS brought to the lives of some women. They all had children who were positive, and although Aarti was asymptomatic, both the others had been diagnosed with AIDS. These women had no one who would look after their children if they died. Kumud repeated anguished questions, over and over again throughout the interview:

***“But who will look after my children when I am gone? Who can love them like a mother? What if they are all separated? My daughter does not go to sleep if I am not there!”***

Aarti was terrified that her child would die before her, at the same time she was terrified of dying before her. She was faced with heart-breaking dilemma, with questions for which no one seemed to have an answer:

***“I am getting weaker ... I do not know how long my daughter will survive, and what will happen after that. This is a cruel game of life. How can I want my daughter to die before me; how can I live if she goes? But who will look after her if we both go?”***

The accounts of Prabha (B.5) and Champa (B.10) reflected grief and loneliness of a different sort. Both of these women felt that they were stripped of their humanity and isolated from others because of HIV/AIDS. Prabha pointed out that the other women in the brothel, who had been her friends before she was diagnosed, were now afraid to come near her, to touch her, or to allow her baby to get close to them. Champa blamed HIV for making her destitute and totally isolated. Both women spoke rather expressively about how sharing their accounts with me had been a salve

for them, because they had been unable to talk with anyone else about the things they were experiencing.

Aditi (B.2) and Janetta (E.25) spoke about how they were unable to accept that HIV had changed their lives so negatively. Aditi said that it had made her a chronic worrier and a very grave woman, who found it difficult to smile or laugh. Janetta's account also reflects issues of grief. She said that everything that had happened to her had changed her completely. She found it difficult to find meaning in anything, or feel happy about anything. She also spoke about feeling very weepy all the time and finding it difficult to control her tears. She did give some indications of hope, however. She pointed out that of late she had begun to laugh and enjoy the company of her sibling's children, and it helped her to relax.

For these women, grief and worry dominated their lives, and they were unable to move beyond their concerns to find new meaning in their lives. They seemingly had lost too much from lives that were already marked by vulnerability and pain. Their stories underscore one of the most difficult realities of the HIV epidemic, its tendency to strike those who are the most vulnerable.

The more unexpected finding of this study, however, is the number of vulnerable women who were able to transcend their losses and move forward, transforming their lives for the better. The next section explores the role that the phenomena of acceptance and hope played for the women in my study.

## Acceptance and Hope

Kubler-Ross (1969) suggests that acceptance is the fifth and ultimate stage of the grief process. The accounts of the women in my study reveal the different aspects of acceptance that they experienced. Acceptance seemed to take two distinct forms for the women in my study. Some women experienced a positive, peaceful sense that things were happening as they should. Other women exhibited a different kind of

acceptance, one born of hopelessness and despair. In addition to acceptance, the prominent emotion of hope ran through the women's accounts, hope that was focussed around their own futures, but also hope that was largely altruistic in nature, and focused on the happiness and future of their children. These women also hoped for a cure for HIV/AIDS that would relieve the suffering of other positive women and people living with HIV/AIDS.

The accounts of the majority of the women reflected the strength that they possessed in trying to remain positive, accepting, and hopeful in the face of HIV/AIDS, which made dramatic changes in lives that were already riddled with vulnerabilities and loss. Despite being faced with a stigmatising illness that took away many things that were important to them, these women managed to find a way to survive and to look upon their lives with hope and acceptance.

## **Acceptance**

The accounts of Namita (B.3), Parul (B.4), Leela (B.6), Marcia (E.26), Julia (E.16) and Jasmine (E.17) reveal that their positive belief in fate, destiny or karma led to the acceptance of HIV/AIDS in their lives. This attitude of acceptance seemed to be one form of positive transformation, characterising women who had faced the realities of their lives and come to terms with them. One example is Namita, who spoke about her complete acceptance of whatever came to her because she believed that whatever *karma* brought was fair and just. Marcia (E.26) echoed her words. She too spoke about accepting whatever life brought her. She said:

***"I have deep faith that whatever life brings me is right for me. I know that in the end I have to accept whatever comes to me, so I might as well do it willingly and readily. "***

Jasmine (E.17) spoke about her deep faith and belief in the Indian concept of karma or destiny. She said that her faith had helped her to accept what life had brought to her:

***"I have become very spiritual. I am a very calm person and believe in goodness and karma. I believe in love and God. I do believe that as you sow,***

***so shall you reap. I have a great faith in nature and being one with nature and goodness, and know that I only get what I truly merit.”***

All of these women reported a sense that what they have experienced was fair, and this belief had brought them a calmness and peace. They were not struggling to change what could not be changed, but instead were finding new ways to experience their lives and to appreciate the time that they have.

The accounts of seven of the women reveal a coming to terms with and an acceptance of HIV/AIDS in their lives as well as an acceptance of themselves and others. Many of these women spoke about their feelings of amazement or incredulity that they had not died and “had been saved” (Allison’s words). They believed that they were saved for some sort of purpose or reason, and this understanding, helped them to accept HIV/AIDS in their lives. Andrea’s explanation illustrates the feelings of these women:

***“I must have been saved because of some reason ken; otherwise, I don’t believe that I would be sitting here ... I’m just fair pleased that I am sitting here when so many friends and lovers never had a chance ... I never thought that I would come to this stage in my life, but I accept HIV in my life. There has to be a reason why I’m not six foot under.... ”***

Interestingly, several women spoke of their acceptance in terms of a voyage. Their accounts reflect the idea that accepting their positive status had led to a “voyage of discovery” (Julia’s words) or a “journey with different changes” (Jasmine’s words) that in turn led to transformations in their lives. Molly (E.21) and Belinda (E.22) emphasised the fact that this acceptance had brought about a great change in them. Belinda remarked that she did not feel like the same person.

Susan’s (E.19) interpretation of acceptance was different from that of any of the other women. She said that when you totally accept something, it is over and done with in your mind. That was her explanation for remaining totally asymptomatic for over 15 years.

In contrast, the accounts of nine women revealed that their acceptance of HIV/AIDS in their lives consisted of a sense of resignation and endurance, a fatalistic approach to destiny. These women said that they accepted whatever came to them because

there was no other way out. Many of these were the same women who had been unable to make positive transitions and transformations in their lives, either because their problems were so grave or because they were subject to ongoing oppression and abuse. These included Prabha (B.5) and Kumud (B.7) who were terrified about who would care for their children when they died, as well as Savita (B.13), Priya (B.14), Lakshmi (B.15), Champa (B.10), and Rashida (B.12), who lived with oppression. These women experienced abusive and unhappy marriages that had been instrumental in making them positive, and they had difficult lives even before they married. In the case of Janetta (E.25) her fatalistic attitude of acceptance seemed to be based on underlying denial of the reality of her circumstances.

## Hope

Hope was like an anchor that provided psychological support (Kubler Ross 1997b) to the women. Hope appeared to infuse the lives of the majority of the women, and may have provided them with the strength and the reason to struggle in the face of great adversity. The hopes of the women revolved around four key issues: hopes in relation to children, hopes about a cure, hopes of living and dying with dignity, and finally hopes of helping and reaching out to other positive persons.

Without any exception, all of the women who had children spoke about their hopes for their children's futures, as discussed earlier in this chapter in relation to how being positive transformed the way they felt about death. Women expressed an ardent, deep hope that their children would have easier lives than theirs, that they would "become someone" in their lives (Molly's, Belinda's, and Nisha's words); that they would be "at peace" in their own lives (Cynthia's words). When Jasmine spoke about her dreams for her children, she referred to Khalil Gibran's ideas in *The Prophet* about children. She said:

***"You know your children do not really belong to you... The Prophet says that they are given to you to love and to help grow and develop ... makes a lot of sense".***



Leela (B.6) and Rashida (B.12) hoped that they would stay well and alive until a cure was available. Leela hoped that her son would someday become a doctor who would work with positive people. Despite her humble origins and her own lack of education, Leela had these high ideals for her son. She said:

***“God should keep me well until my son grows up. I want him to be a very big man, who can do a lot of work for people like his parents. I want him to become a doctor. That is why I send him to a good private English school.”***

Those women who had children who were diagnosed with AIDS, as in the case of Kumud, Prabha, and Aarti, spoke about their hope that their children could be cured. The intensity of their concerns seemed almost as if they were making a plea for a miraculous survival of their child and themselves.

For the women in Edinburgh, who had been diagnosed in the early 1980s, hope showed an evolutionary progress that followed the development of understanding of HIV and of effective anti-retroviral treatment. Nine of these women spoke, as if in one voice, about the changes that had taken place from the early days of the epidemic to the present. In the early days, (many of them referred to them as “they days”) of the epidemic, they were learning to accept the shock of testing positive, as individuals but also as women. For many of them it was a shock because, like the women in Bombay who were infected nearly 10-12 years later, they did not think HIV happened to “decent women,” “married women,” or “older women”. The women in Edinburgh said that they had believed that HIV and AIDS was a gay man’s illness. Most of them recalled how they were too shocked and horrified to have much hope for themselves. Marcia’s account articulates this feeling. She said:

***“In they days, it was like getting’ a death sentence, now there is more hope. Sure you learnt to accept it, but it would be fair to say it wasn’t easy; na, it has to be easier for folks now, but you prayed for all the same things to God....”***

Wilma picked up a glass bowl from her table to metaphorically explain the concept of hope and how it had changed with time. She asked me to imagine that she had thrown the bowl on the floor and broken it into several big and small pieces. She asked me if I would feel that there was any hope for the bowl, and then said:

***“No...because in they days, the hope was as scattered as these pieces, but in these days the pieces can be put together, and you can have hope for the bowl to sit there again.”***

With the advent of anti-retroviral treatment, many of the women in Edinburgh began to see that they might have hope for surviving indefinitely, and as they realized this, they stopped focusing on death and began to think about living their lives with HIV/AIDS. There were some women in Edinburgh, such as Julia (E.16), Andrea (E.18) and Cynthia (E.24), who were ambivalent about the hope combination therapy offered. Andrea suggested that she had been fairly well for over fifteen years with the virus, but had been having quite a few problems since she had started with combination therapy, and it was “doing her head in.” Julia said that learning to manage her life is what gave her the greatest control over her body and hence the greatest hope in her struggles with HIV. She did not pin all her hopes on the medication.

For the women in Bombay, anti-retroviral treatment was not available at the time they were interviewed. Despite this fact, almost every one of them knew of and hoped for the “miracle cure from abroad” to be available in India. The accounts of most of the women in Bombay reflect their strong hope that a cure would become available in time to save their lives.

A few women in Bombay were notable in their lack of hope concerning a cure. Prabha (B.5) and Champa (B.10) already had AIDS and were rather absorbed with the day-to-day reality of survival. Urmi (B.11) had lost a child, and she was so absorbed with her grief over this loss that she had no hope concerning her own life. Kumud (B.7), who believed that she would not survive until a cure was available, said rather ironically that such a cure was her only hope. She very candidly asked me if I thought a cure would become available in time to save her. I could not answer in full honesty, both because I was truly not in a position to answer, and because the last thing I wanted to do was to take away that little glimmer of hope that she still held.

Champa (B.10) was the only woman who seemed to focus on her own impending death. She spoke about the hope of dying with dignity when I asked her about her dreams and hopes for the future. Several other women in both contexts had alluded to this same hope, but the others had all expressed other, life-oriented hopes as well. They also spoke about dying without pain, although none of them specifically talked about it as a hope. Champa's account revealed a general lack of hope, a fundamental sense of unease and frustration at her life situation. She reiterated that she was constantly aware of her AIDS diagnosis and lived with the fear of her illness being discovered and her subsequent destitution. She said that she was plagued by these thoughts and her only hope was to die with dignity, what she called "without losing her shame."

Finally, it was inspiring to note that several women in both contexts expressed an earnest desire to be engaged in a humane process that transcended their own problems and lives. They spoke about wanting to be of some assistance to women like themselves who had suffered because of HIV/AIDS. Priya (B.14) and Andrea (E.18) exemplified these hopes. Priya said:

*"I hope that someday I can really help other people like myself. Medicine may not be found in my life time, but I would like to talk to people and assure them, listen and share their pain ... I wish that all HIV patients all over the world should have painless deaths and people to understand them."*

Andrea talked about wanting to reach out to other positive women, especially for women in the (Scottish) highlands who do not have a lot of support and agencies to turn to. She said that what was needed was "for positive women, by positive women and of positive women."

## Conclusion

This chapter has discussed the post-diagnosis stage, with its focus on the key issue of long-term adjustment. The phenomena of turning points, transitions, and transformations are relevant to this issue, and the ways that these phenomena can be seen in the lives of the women were discussed.

The phrase “turning points” refers to the key events that changed the lives of these women. For most of the women in my study, the key event that they focused on occurred either somewhat before or after they were diagnosed with HIV/AIDS. In some cases, they focused on events that may have led directly to their own diagnosis, such as being raped or being forced into prostitution. The changes associated with contracting HIV and receiving a positive diagnosis seemed to flow out of these key events. In other cases, they focused on losses that occurred both before and after their diagnosis, such as the loss of partner, sibling or child that seemed to add to their vulnerability to HIV/AIDS. For most women, the various experiences of loss, rather than their HIV/AIDS diagnoses, were seen as the major turning point or epiphany in their lives.

The term “transitions” in this chapter refers to the new journeys or paths that women took on account of discovering that they were positive. Transition implied the beginning or unfolding of a process of change in the lives of the women. It is important to note that the process of transition ‘spilt into’ the other two stages of pre-diagnosis and diagnosis. Moreover, it is important to reiterate that these stages (pre-diagnosis, diagnosis and post-diagnosis) are overlapping, and are to be viewed as broad frames, rather than precise periods. An HIV/AIDS diagnosis marked the beginning of a transition or a change from one set of circumstances to another (Golan 1981). The first harbinger of this change was increased attention to personal care and health.

The phenomenon of “transformation” refers to the ways that living with HIV/AIDS changed the way many of the women thought, lived, and acted. Clearly, they were

different people after having gone through the experience of contracting HIV/AIDS and learning to live with it. Both positive and negative changes were discussed in this regard.

Finally, the chapter discussed the strong, almost palpable sense of acceptance and hope that emerged from the majority of the women's accounts. Their stories relate the up and down course of their hopes—periods of despair interspersed with periods of being hopeful. The stories highlight what Kain (1996) refers to as the profound paradox of being HIV positive, the irony of having hope destroyed while at the same time becoming ever more dependent upon it. This chapter has also discussed how the elements of acceptance and hope sustained the women in their struggle with HIV/AIDS and gave them the ability to somehow emerge as victors.

The next chapter, Chapter 8, takes a more conceptual look at the phenomena of change that were observed in my study. The chapter ties together the three theoretical concepts of the study, turning points, transitions, and transformations, and provides a conceptual framework to understand change in the lives of women with HIV/AIDS.

## CHAPTER 8: TURNING POINTS, TRANSITIONS AND TRANSFORMATIONS

### Introduction

This chapter draws together the three theoretical concepts of turning points, transitions and transformations described in the previous chapters, to develop a synthesized, deeper understanding of the process of change brought about by HIV/AIDS in the lives of these women. The concepts, when explored together, provide a framework to understand the phenomenon of change and to highlight critical events that contributed to this change. Moreover, the three concepts together can be used to create a model that helps us to understand how these women managed great adversity with very limited resources. The way in which women portrayed change and how they coped with adversity in their lives undoubtedly varied from woman to woman; however, there were some essential similarities in the way in which women in both contexts described the changes that HIV/AIDS brought to their lives.

It is important to note that although these concepts of change are theoretical in nature, while conducting the study, I referred to them using non-theoretical, common sense terminology. Thus, when I asked the women to describe personal turning points, I spoke about an event (or events) or a point (or points) in each woman's life that changed her life irrevocably, such that it altered the course of her life. When I asked them about transitions, I talked about the journey (or journeys) that they made or had been forced to make because of the turning points in their lives. Finally, when I discussed transformations, we spoke about their role in life getting redefined or changing significantly.

The conceptual framework of the three concepts of change helped me to devise a model that facilitates an understanding of the changes created by a devastating illness such as HIV/AIDS. Albeit in a limited way, this model, attempts to develop fresh insights into the cyclical aspects of change that occur in the lives of women who



become HIV positive. It aims to bring together my thoughts and understanding of the processes of change in the lives of women living with HIV/AIDS and to draw together the findings of the study and its implications for positive women living with HIV/AIDS and for professionals working in the field. Change is an intangible, complex concept that philosophers over the ages have sought to understand and explain. It is not the intention of this chapter to get involved in a philosophical discussion about the meaning of change. Rather, it seeks to focus on how women perceived turning points, transitions, and transformations and how they experienced changes in their lives.

The concepts of turning points, transitions and transformations are interdependent, requiring each other to be understood. Although the three overlap, are fairly fluid, and are not linear, they seem to follow a pattern where turning points lead to transitions, and, transitions lead to transformations. According to the model I am proposing, the turning point is the trigger event or events that jolted the system of the women; transition is the period or phase of movement, or journey they made, producing a new sense of awareness that led to transformation.

Figure 8.1, below, illustrates the change model I am proposing. I use a circle to depict the process of change in order to convey the idea that the process is not linear. Concerns and issues from one phase of a person's life course can be revisited in later phases, and a process of transformation can lead to new turning points and further transitions and transformations. This figure attempts to illustrate the interplay of the three aspects of change: turning points, transitions and transformations. It does not however, manage to convey the dynamic, iterative nature of change.

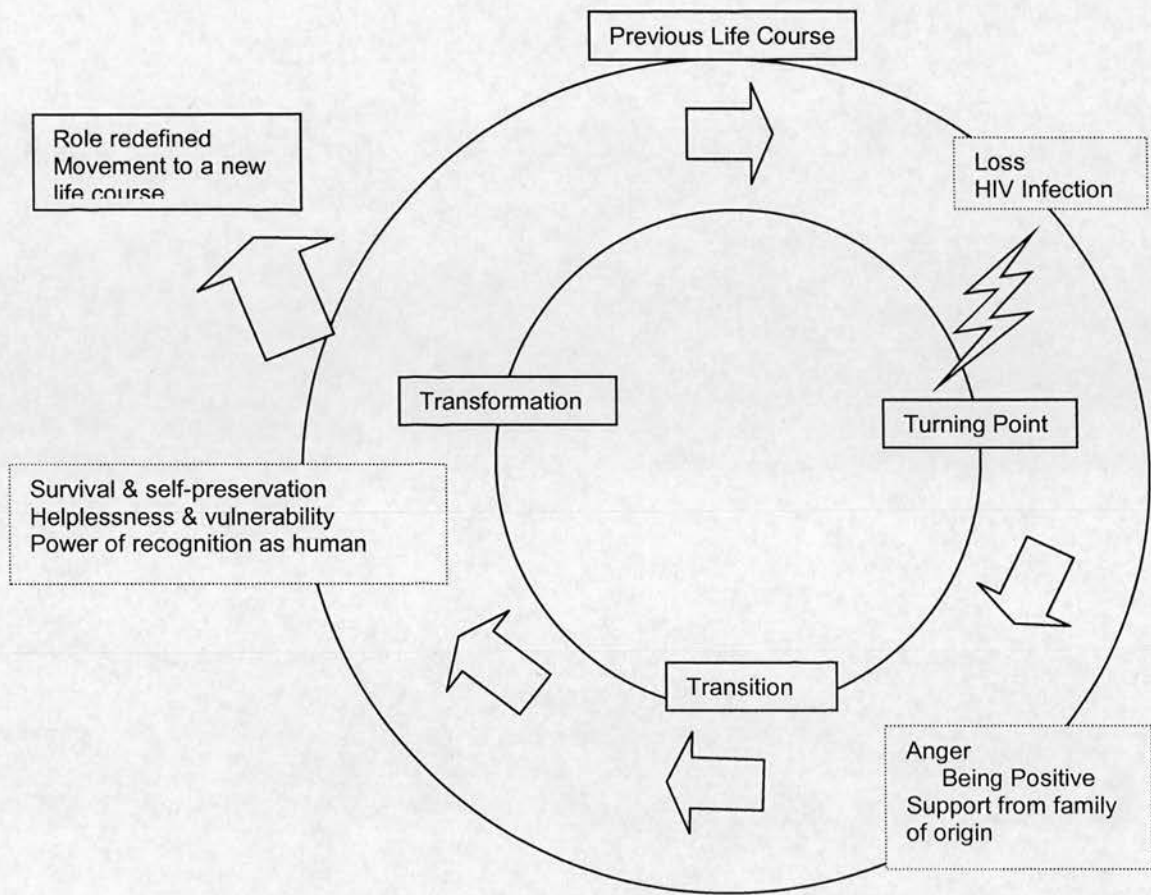


Figure 8.1: A model of change in the lives of HIV/AIDS positive women

It is also crucial to note that although the three concepts of turning points, transitions and transformations seemed to follow some sort of progression, they were not so clear-cut in real life, and were marked by fits and starts and by periods of regression. This is similar to what Kubler-Ross (1969, 1987) suggests about the stages of grief, that they are described as distinct stages, but in fact do not necessarily occur in a fixed order or in a fixed way. Turning points, transitions and transformations are part of an evolving process, with small changes occurring incrementally and gradually making a dramatic difference.

Finally, it is important to understand that the concepts of turning points, transitions, and transformations exist in the literature about HIV/AIDS, but not together, where they depend on the other to be understood more fully, as is the case in this study. The three concepts also exist in other literature. The life course literature focuses on life

trajectories and turning points. Transitions are at times equated with turning points, and at other times, potentially positive or negative life transitions are regarded as instrumental in bringing about turning points across the course of an individual's life (Wheaton and Gotlieb 1997). Moreover, the life course literature points out that turning points, transitions, and trajectories are shaped by earlier life experiences and the personal disposition of the individual (Kohn 1995). Tatelbaum (1981) considers the concepts of transitions and transformations in the literature on bereavement. She suggests, as discussed in the review of literature, that when a person experiences grief, pain, and suffering, he or she is confronted with a profound challenge, following which the person can either give up or can grow from the experience. She points out that when the challenge is used to grow, a positive transition or transformation occurs in the person's life.

Kubler-Ross (1997c) looks at the concepts of transitions and transformation in relation to her own experience of living with a debilitating illness and impending death. She uses the metaphor of the cocoon and the butterfly. Transitions occur at death, according to her, when the person breaks free from the body, out of its cocoon and emerges transformed as a butterfly. Denzin's (1989b) "existential interpretive" perspective examines all three concepts in relation to epiphanies in the lives of individuals experiencing crisis, not necessarily those experiencing illness. He suggests that a turning point is any event or transition that has the potential for transformation. He appears to conceptualise turning points and transitions as the same aspect of change that leads to transformations.

The writings of Kubler-Ross (1997c; 2001) and Denzin (1989b) have played a significant role in my own understanding and exploration of the three concepts in relation to the lives of positive women and, in turn, have enabled me to develop my own phenomenological model that was based on the women's perception of the aspects of change in their lives. While Denzin's (1989b) model provided me with a theoretical understanding of the connections between turning points and transformations, Kubler-Ross's (1997c) metaphor of the butterfly provided me with an inspirational insight into the inevitability of the process of change, which is

difficult to capture as a process, yet easier to see as a final outcome or transformation.

## Turning points

### **The Perception of Loss and the Influence of Trauma**

The idea of a turning point suggests a radical change of direction, brought about by some new event or perception. From my observations, I have concluded that there was a moment, in the majority of the women's lives, when something they experienced did change their lives in a profound way. I had anticipated that the women would see the HIV/AIDS diagnosis as a major turning point in their lives, but, as noted in chapter 6, a large majority of the women placed emphasis on the experiences of loss that had shaken their lives. They perceived as turning points the losses that had left them vulnerable.

Wethington et al (1997) suggest that by definition, a turning point is a psychological process that involves a change in awareness, or a new insight into the meaning of things. Denzin (1989b) suggests, as described in chapter 2, that epiphanies or turning points in the lives of individuals are those moments that have the ability to change the lives of the individuals, such that their lives are never the same. As I understand the word "epiphany," it also seems to imply a new kind of knowledge or awareness about oneself. For my respondents, their experiences of loss, as well as their diagnoses with HIV/AIDS, forced these women to think of themselves differently.

For some of the women in my study, loss led to a change of status and identity. Women in Bombay who became widows were forced to think of themselves differently because their culture ascribed a new (and less desirable) role for them. Similarly, those who lost children adopted the new role of bereaved parent. And, for a few in Bombay, the role they assumed was that of a victim of domestic violence. These women experienced loss of their freedom, personal safety, and self-determination when they married into abusive situations, and this is the loss that they

focused upon. Their new status as victims implied powerlessness and hopelessness, with no obvious means of escape.

For a few of the women, loss of their previous roles led to empowerment. For these women, loss gave them a new, positive sense of identity. It seemed to instil in them a new sense of purpose and achievement, which gave them the strength to struggle and overcome their addiction to drugs. In all of the loss situations described above, the women had to give up a previous identity and assume a new one because the role they had played before was no longer available to them.

But why did they choose to focus on these losses rather than on the very real threat posed by the diagnosis of HIV/AIDS? One possibility may have to do with the ambiguous nature of HIV/AIDS. It is possible to be infected with the virus for years before experiencing any symptoms, and several of my respondents were in relatively good health at the time of the interviews. Perhaps HIV and AIDS did not seem particularly relevant to them, especially in comparison to more immediate experiences of very tragic loss. Even for those who were symptomatic, there was uncertainty as to how immediate the threat to their health actually was. For the women in Bombay, many of whom were relatively uneducated and unsophisticated; HIV and AIDS may have seemed like rather vague scientific concepts that had little meaning for them in their day-to-day lives.

For the women in Edinburgh, there was the added element of uncertainty created by the availability of combination therapy. The women who had access to this medication may have thought of HIV in a different way, because they had a real hope that medication could delay the onset of AIDS indefinitely. For these women, it is possible that the advent of combination therapy and the phenomenon of more and more people living healthier lives created a shift in their consciousness, from waiting to die to learning to live with HIV/AIDS. Perhaps the hope created by combination therapy has been responsible for shifting the emphasis from the all-consuming entity of HIV/AIDS back on to themselves. Thus, they would focus on the enormity of the loss experiences in their lives, rather than on HIV/AIDS itself.



Another reason for the focus on loss may have to do with the degree of trauma that many of these women had experienced. One common symptom that people experience in reaction to a traumatic event is a tendency to re-experience the event, through intrusive memories, thoughts, and dreams (van der Kolk et al. 1996). Perhaps the women were so caught up in this process that they focused on their traumatic loss experiences and paid much less attention to other important experiences.

For some of the women, whose traumatic experiences led to their infection with HIV/AIDS, the focus on the trauma might also be part of the recovery process. When people experience traumatic events, it is not unusual for them to think about the circumstances that led up to the event, wondering over and over again if the bad thing could have been avoided. Some of the women in my study may have been focused on the experiences that led to their HIV/AIDS infection, wondering if they could have escaped infection if something had happened differently in their lives. This may have been the reason that they did not mention HIV/AIDS diagnosis as the turning point, instead talking about the traumatic losses that put them in danger of infection. The accounts of some women reflect how they centred around the traumatic events of loss that led to their diagnosis rather than on the diagnosis itself.

Finally, perhaps loss associated with HIV/AIDS is more tangible and palpable than experience of diagnosis itself. This might be true even for those women who had experienced some of the debilitating effects of HIV/AIDS or others who had vicariously suffered with their loved ones who suffered and died with AIDS. Multiple losses have been described as the hallmark of this epidemic (Shernoff 1992), and loss may have actually defined HIV/AIDS for the majority of my respondents.

Regardless of the reason, these women chose to focus on loss experiences and to recall these as important turning points in their lives. Since my study is explicitly phenomenological in nature, it is important to recognise this fact and to emphasize the women's perspective. Other researchers who work with similar respondents



should be aware of the difference between what they expect and what their respondents actually feel and experience. Women in these circumstances may not think that HIV/AIDS infection is the most important experience they have had, and they may instead focus on the many complex experiences of their lives, some of which are closely connected to HIV/AIDS infection, and some of which are not.

## Transitions

The humanist perspective presumes that human beings have an inherent capacity to reorganise and restructure their lives, and, in so doing, they gain a new insight into their life experiences. For most of the women in my study, the experience and acceptance of loss and the pain and adversity that accompanied it appeared to make them stronger (Kubler-Ross 1997c) and to facilitate a transition. The knowledge that they were living with a chronic, stigmatising, and potentially fatal illness, along with the strong feelings of anger expressed by the majority of the women, seemed to be a motivating force or power that propelled women into change, often compelling them to make a transition or a discontinuity in their life space (Adams et al 1977). Moreover, the support that women from both contexts received from their social support networks seemed to play a significant role in facilitating transitions.

### Role of Anger

Several studies point to the therapeutic value of anger and conclude that terminally ill patients who are angry live longer (Kubler-Ross and Kessler 2001). Studies of AIDS long-term survivors also found anger to be the predominant emotion that was elicited and reported (Rabkin et al 1993). While unfocused, chronic anger can be a negative influence in a person's life, anger can also be a source of energy that propels the individual to make changes. Anger seemed to have this kind of positive impact for a number of the women in my study.

For some women, the anger they experienced may have been the energizing force that helped them to move forward and to begin to take charge of their lives. Perhaps anger also provided the wherewithal for women who were so severely traumatized to

adapt and push on (Gondolf and Fisher 1988). Some of the accounts reflect what feminist literature talks about: anger as an empowering force that allows women to change situations in which they are victimized (Worrell and Remer 1992). Anger might enable a previously powerless person to find some sort of personal power that allows them to do things that were previously impossible for them. Anger could also be directed at one's situation in life, including illness itself.

On the other hand, anger might sometimes be an obstacle to moving forward. Lauzon (1997) suggests that individuals need to completely leave behind their old perspectives if they want to engage in the healing process, and this phenomenon seems to be at work in some of the accounts.

### **Role of Being Positive**

Being HIV/AIDS positive brought several changes and life transitions for the majority of the women. These transitions appeared to provide a crucial condition for development, (both positive and negative) by making it necessary for the women to absorb the new experience (Moos and Schaefer 1986). It was necessary for the women to begin to think of themselves and of their lives differently in order to make the many changes necessary in order to adapt to the presence of HIV in their lives.

Several women spoke about an inspirational or philosophical impact that HIV diagnosis had on their thinking. A number of women said that being positive had taught them to value time and to value themselves. Perhaps, faced with the untimely end of their lives, these women came to see the time they had left as more precious, and to focus on things that had not seemed important previously.

A significant number of women emphasized that being positive encouraged them to improve their interpersonal relationships and made them more patient and tolerant. This was particularly predominant in the Edinburgh sample, and may reflect cultural values that emphasize interpersonal relationships. The issue may also have been less salient for the Bombay women, who were so occupied with the realities of daily survival.

For some of the women, particularly those who had to struggle for day-to-day survival, the addition of HIV to their lives was perceived as yet another threat and burden. These women talked about how being positive made them fearful, anxious, and unsure of what course they should take in their lives.

For all of the women, the advent of HIV in their lives meant that they had to think and behave differently. Their choices in regard to the new ways of thinking were likely influenced by a number of factors, which are described in the next section.

### **The Role of Individual Characteristics and Support Systems**

Williams (1999) argues that in the same way as the fight and flight response enables an individual to cope with danger, the process of transition enables adaptation to trauma and change. Coping and living with the changes that were brought on by the turning points in their lives (the varied experiences of loss, both before and after diagnosis, and the HIV/AIDS diagnosis itself) brought to the forefront fundamental issues of human survival. To cope with these, the women I studied utilised powerful survival mechanisms (Williams 1999) of transition to adapt and to reshape their lives.

In the case of these positive women, the transitions involved the process of making decisions and figuring out how to move ahead or carry on with their lives. For some women, the transition process was one of empowerment and self-discovery. For others, the transition was marked by confusion and fear.

The nature of the transition period may have reflected individual strengths and weaknesses of the women, as well as resources available to them to help them cope with the upheaval that was taking place in their lives. While it is difficult to pinpoint what it was in the women's lives and natures that encouraged them to make positive or negative transitions in their lives, the women's accounts suggest some important influences. One factor seems to be economic stability. Although they were still quite poor, the majority of the women in Edinburgh were comparatively more stable

economically than the women in Bombay, and many of the Edinburgh women made fairly positive changes. Among the women of Bombay, some of the most destitute had the greatest difficulty adjusting and adapting. For these women, already living on the edge, the advent of HIV was particularly devastating.

Another important factor seemed to be the availability of some kind of support system. Women, who had supportive networks or those who had support from a partner or from family, seemed to fare a little better.

Physical and mental health and well being at the time of diagnosis also seemed to make a difference. Many of the women who adapted fairly well were still physically well. Some women also talked about taking time for themselves, focusing on their mental and spiritual well being. It seems likely that being able to spend quality time with oneself facilitates some amount of self-awareness and personal growth.

Education seemed to be another important factor. Some of the women in Edinburgh who had at least some education had clearer goals for their future. They envisioned a future that went beyond the traditional roles of wife and mother, as might be expected for women who had received education in a modern, urban society. On the other hand, women who never really had a chance for education had worldviews and aspirations that were more tied to family life. When that aspect of their lives received a blow through the advent of HIV, it left them even more vulnerable and perhaps less capable of making a positive transition.

Finally, one observation seems quite paradoxical. A few of the women I studied, who had little dignity, who were very oppressed, whose lives were very marginalized and stigmatised, were able to make positive transitions. The very enormity of HIV diagnosis, and the nature of the turning point itself seemed to be what made a difference to these women. Perhaps for these women, the turning point comes as a catalyst, a jolt that pushes them out of their negative life course. This may be analogous to the phenomenon that many reformed alcoholics and drug users have experienced--a chance for redemption.

The transitions that women experienced in their lives led to transformations and a redefining of their roles and who they were as individuals. The next section discusses this aspect of change.

## Transformations

The concept of transformation is an inspirational one, however, it is not a fairy tale concept, and does not always have a positive ending. Like the concepts of turning points and transitions, transformation also symbolizes change and movement. However, just as movement is not always forward, so too change is not always positive. Transformation in the lives of my respondents consisted of a redefinition of self, either through changes that they perceived as positive, or through changes that they perceived as negative.

### **The Power of Being Recognised As a Human Being**

The accounts of the majority of the women in my study revealed that they made dramatic positive changes in their lives instead of surrendering to the anguish and the hopelessness that one would normally expect to overpower the lives of individuals who were so subjected to crisis, abuse, and varied struggles for survival. One of the reasons for this response could lie in the need for survival and self-preservation, which are both strong human instincts. The literature on terminal illness is filled with experiences of terminally ill persons who discover new meaning in their lives and are motivated to make extraordinary transformations, following the experience of great loss and tragedy (Kubler –Ross and Kessler 2001). Another reason could be that some women were able to dramatically change or transform their lives because the diagnosis of HIV/AIDS provided the momentum, or the force, or the motivation to do so.

However, I believe that for many of the women I interviewed, these transformations went beyond the need to survive. There was something equally strong or even



stronger than that: a theme that seemed to run through the life stories of many women. This was evident in what the women were saying as well as in what they were not saying, but were conveying indirectly. I definitely got a sense that many of the women in both contexts made these transformations because they were treated with some amount of kindness and compassion, with dignity, as if their lives really meant something. Their diagnoses seemed to provide them with the opportunity to be treated differently, often for the better. Some of these women had experienced such chronic hopelessness and extreme vulnerability in their lives, and the dignity and human worth that they were shown as HIV/AIDS patients seemed to empower them and help them to transform their lives.

This was especially true of the women in Bombay who were able to talk to counsellors at ARCON and receive support and respect, perhaps for the first time in their lives. This attention that they received after their diagnosis was a new thing for most of these women, whose lives were so downtrodden. After a lifetime of being told that they were worthless and nothing, to be looked upon as important and worth the effort of treating and saving seemed to be a transforming experience. For a few of these women, the only good thing that had happened to them in their lives was the attention that they had received from the staff and doctors at ARCON and from me. This observation is a tragic commentary on the reality of worthlessness that some of these women experienced.

Similarly, some women in Edinburgh recalled the care and dignity that they received (in addition to various kinds of social supports and services), from Solas and other voluntary and governmental organisations. After years of leading a chaotic existence that arose from the nexus between drug use, sex work, and abuse, to be considered as worthy of respect and compassion was something that changed their lives.

Finally, I believe that the experience of respect and recognition was an important factor in encouraging some women to reach out to other women living with HIV/AIDS, who were less fortunate than themselves or who were completely lost and did not know anything about the deadly illness. The respect and self worth seems to have provided some women with motivation to reach out to others, despite their



problems. Several women spoke about their deep aspiration to be able to reach out to other women, like themselves, who had suffered and continued to suffer in silence because of the yoke of HIV/AIDS and various forms of injustice.

In concluding this section on transformation, I would like to emphasize that although the HIV/AIDS epidemic has brought much devastation and even further stigmatised and marginalized vulnerable women, at the same time it has also created a care response that has resulted in many women being immersed with attention and compassionate care for the first time in their lives. It is tragic that these women had to contract a terrible illness like HIV/AIDS in order to finally be recognized as worthy of human respect and dignity.

This may also have been one of the reasons why women expressed so much gratitude to be involved in my study. It was perhaps because they were responding to the unsaid, almost visceral message that they were worthy of attention, dignity, and compassion, and deserved to be treated as special human beings who had experienced so much in life by living with a complex, chronic, and often fatal illness like HIV/AIDS. This idea about transformation links into the notion of the “power of stories” as a transformational experience, which is discussed in the chapter on methodology.

## Conclusion

This chapter ties the women’s experiences in relation to the aspects of change to the three theoretical concepts of turning points, transitions and transformations. It demonstrates how the women viewed turning points, often seeing losses rather than HIV/AIDS itself as events that completely changed their lives, which might have been related to their need to explain the troubles, and adversities they had lived through to themselves. It shows how the losses they experienced and the state of being positive led to transitions, in various avenues that fit the circumstances of each individual. And finally, it explores the aspect of transformation that occurred in the

lives of several women. It was a result of loss, being HIV positive, but also by gaining validation as a human worthy of respect, attention, and help.

The three aspects of change in the lives of positive women could be seen as a wheel, where turning points marked the beginning of the process, transitions marked the unfolding of the journey, and transformation was the outcome. Because change is viewed as a wheel it is circular and the process is an evolving one.

The next chapter is the final chapter of the study. It concludes the study by summarising the findings, discussing implications and limitations of the present study, and presenting implications for future research and some final observations.

## CHAPTER 9: CONCLUSION

### Introduction

The purpose of this chapter is to summarize the findings and to discuss the nature of the contributions made by this study. The first section briefly describes the substantive findings that emerged in relation to the research question. The next two sections discuss the Implications of this Study and the Implications for Future Research, followed by the Limitations of this Study. The chapter concludes with some final observations.

### Summary of Findings

The finding for the Pre-diagnosis stage concerns the issue of vulnerability that was discussed in Chapter 2. Based on the accounts of the respondents, I found that HIV/AIDS came to lives that were already vulnerable or “capable of being hurt” (Heinemann 1985). The women experienced individual, social, and structural vulnerability that contributed to their risk of contracting HIV/AIDS.

The findings that emerged from the Diagnosis stage reflect the key issue for this stage, which concerns the immediate impact of diagnosis. The immediate impact of a positive HIV diagnosis was reflected in anger. The women’s reactions seemed to fit with Kubler-Ross’s (1969) second Stage of Grief, which focuses on anger or resentment. These women reported experiencing anger towards the people, circumstances and chance occurrences that led to their infection with HIV.

Four findings related to the issue of long-term adjustment emerged from the post-diagnosis stage. First, loss was perceived as a major turning point or epiphany for a majority of the women in my study. Different kinds of loss (Sherr 1995b; Teguis and Ahmed 1992) were described as key experiences of their lives before, during, and after their HIV/AIDS diagnoses, and they focused on these losses rather than on the

discovery of a positive HIV diagnosis itself. Although the women seemed to understand that the HIV/AIDS diagnosis had a tremendous impact on them, only seven out of the 27 women interviewed chose to focus on the diagnosis as the key turning point they had experienced.

Second, HIV/AIDS diagnosis marked the beginning of a transition (Tyhurst 1957, Hopson and Adams 1976, Golan 1981, Vaughan 1986 and Brammer 1991) in the lives of majority of the women. After learning of their diagnoses, they began a complicated and often difficult process of reshaping their lives, often because they had no choice. For many of the women, the first evidence of this transition was a change in their self care. They began to pay more attention to issues such as getting adequate nutrition and receiving medical care, things that they had often ignored before discovering their HIV status.

Third, HIV/AIDS transformed the women's lives by affecting many important aspects of their being (Squire 1993, Christ and Weiner 1985, Lehman and Rusell 1985, Mane and Maitra 1992). HIV/AIDS irrevocably changed these women (Herek 1995, Miller et al. 1994), perhaps because it changed so much of what the women had come to know as normal in their lives. They experienced changes in their behaviour, their values, their attitudes about many fundamental issues, their way of living, and their perception of life.

Finally, most of the women experienced acceptance of the reality of their life situation and the capacity to hold hopes for their future (Kubler-Ross 1969). For the women who were able to transform their lives, the experience of being respected and recognized made a difference. The ability to tell their stories also seemed to serve as a positive influence for the women.

The changes experienced by these women could be understood in relation to three important concepts of change: turning points, transitions, and transformations. I have proposed a model, based on the women's perceptions, that attempts to draw together the three concepts to explain the process of change in reaction to HIV infection. In this model, change occurs as an evolutionary process, which is set in action by a

crucial event, or turning point, that disrupts the person's life course. This disruption leads to a transitional stage as the women try to adapt to the many changes in their lives. Ultimately, the changes become such that they amount to transformation, the development of a new life course, marked by different behaviour, attitudes, and perceptions.

## Policy Implications of the Study

The insights gained from the study led to several implications. The first is a crucial need to create gender sensitive policies and programme environments for women and their children living with HIV/AIDS. Policies need to address issues of gender inequality, which are at the core of the spread of the epidemic (Villarreal 2000). Due to the power differential that exists between the sexes in socially and economically deprived groups, women have very limited power to assert their rights to avoid the behaviours that can lead to infection with HIV/AIDS.

From birth, women are socialised into dependency more than men are, and this gender role affects all their relationships: marital, non-marital, and sex work (Berer 1993). Their concepts of femininity and masculinity, along with the gender and power relations, limit the capacity of women to negotiate the boundaries of their sexual encounters (Holland et al. 1992). There exists, as borne out by the accounts of the respondents in Bombay, a standard that appears to permits men to have sexual freedom, regardless of marital status, while sexual freedom is stigmatised for women (Ward, 1993). This creates a sexual imbalance of power between men and women that denies women the ability to negotiate sex and the issues surrounding it, thereby leading to behaviours that increase their risk of HIV infection (Reid 1992, Ward 1993, Quinn 1993, Berer 1993). For many women throughout the world, issues of self-protection are intimately linked to their lack of power to negotiate in sexual encounters.

The media perpetuates this power differential by directing people to participate in honest discussions with their sexual partners about their sexual history. This suggestion holds little credence for women in relationships with an unbalanced distribution of power. Poor women are often subservient to their partner's wishes and may have sexual arrangements that do not encourage 'middle class notions' of communication (Ward 1993). Poor women are also less likely to ask men about their sexual histories because they know men will lie or discount the risk (Cohan and Atwood 1994). Moreover, women irrespective of their social context are often treated as the second sex by men, as reflected in the lives of the respondents who experienced rape, sexual abuse, assault, forced prostitution and other forms of marital and non-marital violence.

Poverty interacts with gender imbalances and prevents women from protecting themselves. For many women who are in a relationship, there exists an economic dependence upon their male partner to avoid poverty for themselves and their children. Because of this dependence, women find it difficult or impossible to question their partner's sexual history or drug use history, or to negotiate safe sex practices to protect themselves from infection.

Women living in the grip of poverty, unable to sustain their families, are forced into "sexual networking" as a means of survival (Berer 1993, Doyal et al. 1994). Economic desperation forces women into sex work where they have little or no say with whom they engage in sex, or, whether they can protect themselves. More often than not, this is not a behaviour of choice, it is one of necessity. Schoeff (1993) argues that sex work for many women is an occupation born out of a cold and stark economic necessity and their need to survive. She concludes that with the advent of HIV/AIDS, women's strategies to survive have turned into death strategies. More crucially, even when women do understand that they might be putting themselves at risk, their immediate survival issues are more relevant to their daily lives (Mays and Cochran 1988, Packard and Epstein 1991, Schoepf 1995, McGrath et al. 1993, Preston-Whyte 1995, Collins and Rau 2000, Loewenson and Whiteside 2001). Tangible concerns such as starvation or homelessness can become so overwhelming



that a disease, which may or may not manifest itself after a few years at best, becomes a secondary concern (Ward 1993, Cohan and Atwood 1994, Hankins 1997).

Finally, women who use drugs experience another level of powerlessness related to their use of drugs. Drug use increases their chance of contracting HIV/AIDS in two ways. There is the obvious risk from sharing needles, but there is also the risk associated with higher likelihood of unprotected sex, either in abusive relationships or in the exchange of sex for money in order to purchase drugs (Connors 1992, Quinn 1993, Cohan and Atwood 1994).

This study highlights the need for developmental programmes to empower women through education, awareness, information, and support so that they can challenge the structures of oppression that dehumanise them and make them vulnerable (Hsu and du Guerny 2000) to HIV/AIDS. As demonstrated in this study, women's vulnerability to HIV/AIDS is enhanced by factors such as poverty, economic dependence on men, lack of access to education and health facilities, abuse and violence, myths and beliefs that disempower them, and conditions that coerce them into selling sex for survival or to support a drug dependency.

A second implication of the study is the need for education, particularly education of men. Men need to understand the risks they expose themselves and their families to when they engage in risky behaviours: unprotected sex, drug use, and alcoholism. Education in relation to unprotected sex with sex workers is particularly important in the context of Bombay, as reflected in the study. Equally important is the education for men who, for fear of stigmatisation, deny their bisexual orientations, thereby increasing the risk of HIV/AIDS infection. Men, who migrate because of economic necessities and live away from their families, or truck drivers who are away for long periods of time, pay for sex and use alcohol and drugs as a way to cope with the stress and loneliness of living away from home. Men need to be socialised to take more interest in the health of their families and their own health. Piot (2000) points out that changing the attitudes and behaviours of men has enormous potential to slow down the HIV/AIDS epidemic, and to improve their lives and the lives of their

partners and families. Despite highlighting men's issues and the role of educating men, women's voices need not be silenced, nor should they be further marginalized. Berer (1996) suggests that men should be involved in ways that are supportive of women and their concerns. She argues that to empower women, policies for change that involve men must necessarily be grounded in a woman-centred and gender-sensitive perspective.

Additionally there is the need for education and awareness of the general population in order to prevent or reduce stigma and shame. This is crucial given the uniquely stigmatising impact of HIV/AIDS, both in the context of developing and developed nations (Obaid 2002). Stigma experienced by women in this study reduced their ability to obtain treatment and heightened the trauma of their diagnoses. The respondents from Bombay experienced severe stigma and shame from their families of marriage, and a few from medical professionals. It was the converse for the respondents in Edinburgh. The greatest stigma and shame they experienced was from the medical profession. One respondent from Edinburgh experienced stigma and shame from her family of origin. This indicates the need for education and awareness among the varied strata of society.

Since the beginning of the epidemic, HIV/AIDS -related stigma has been recognised as a problem (Parker and Aggleton 2001). However, it needs to be studied more extensively by social and behavioural scientists (NIMH 1998). An awareness of the varied social, cultural, and psychological aspects of stigma is required, to inform medical professionals, politicians, religious leaders, persons living with HIV/AIDS, and society at large through the media. An understanding about the nature of HIV/AIDS and its transmission is crucial if the cycle of stigma, discrimination and shame experienced by the respondents in this study is not to be perpetuated.

The third implication of this study concerns human rights issues in the context of India and other developing nations. UNAIDS (2002d) eloquently argues that in the world of HIV/AIDS, the paucity of human rights protection can become a matter of

life and death. Assessing HIV/AIDS in the framework of human rights will help to stem the growth of the epidemic and reduce its toll on human suffering.

All the respondents in Bombay belonged to strata of society who were unable to access their fundamental human rights. Articles 25 and 27 of the Universal Declaration of Human Rights uphold the rights of individuals to “the highest attainable standard of physical and mental health” and “to share in scientific advances and their benefits” respectively (UNAIDS 2002d). The fact that women were deprived of their right to health was reflected in varied ways in their accounts: inability to buy nutritious food, inability to buy medicines, inability to protect themselves sexually from being re-infected by their partners, lack of support services, and the lack of social controls over cruel structures of oppression and misinformation.

The fact that anti-retroviral treatment was not available to respondents in Bombay highlights the fact that these women were unable to share in the scientific advances that other women in India who are not poor are able to benefit from. Farmer (1996) argues that the advances in science create, maintain, and deeply entrench disparities between those who are able and those who are not able to reap the benefits of the scientific revolution. He refers to this aberration of human rights as structural violence. He suggests that structural violence is visited upon all those individuals whose social status denies them the right to the benefits of scientific progress.

A fourth implication of the study is the importance of encouraging connectedness to family of origin as a means of coping. Psychological well-being of people with HIV/AIDS is increasingly linked with the support they receive from family, friends and community (Bor and Elford 1994, Ramien and Rabkin 1995). The benefits of social networks are well established for coping with stress (NIMH 1995). Social support could be experienced as emotional, tangible, or informational support. The support that persons receive from their social networks protects them from negative experiences such as emotional distress, isolation, and negative emotions that result from stressful life events. Additionally, kinship ties play a particularly crucial role in

the lives of persons with HIV/AIDS. These people must rely on family members for support because other avenues of support are often not available due to the stigmatisation of HIV/AIDS. They experience discrimination irrespective of whether they belong to a more traditional society characterised by “conformity and traditional values” (Scheff 1994), like that in Bombay, or a modern society characterised by “individualism and isolation” (Scheff 1994), like that in Edinburgh.

Finally, this study has differential implications for the need of testing and supportive services for positive women in Bombay and Edinburgh. Women from both contexts suggested that pre- and post-test counselling was an important factor in the acceptance of an HIV/AIDS diagnosis. The majority of the women in Bombay received pre- and post-test counselling. Pre-test counselling consisted of brief information sharing about how HIV/AIDS was transmitted and the implications of a HIV/AIDS diagnosis. After women received a positive diagnosis, they were given more intensive supportive counselling. Most of the women recalled that this support they received from the counsellors was invaluable in helping them to prepare and accept the HIV/AIDS diagnosis. Interestingly, many of them also reported that although facts about HIV/AIDS were “carefully explained”, they were unable to understand many things at the time because of their emotional reaction to the diagnosis.

Some of these women suggested that it was vital for women to be mentally prepared for the diagnosis. Two of them suggested that the government should force men who are positive to have their partners tested, and if they were unwilling to get their partners tested, they should be punished or fined. One woman believed that this would prevent husbands from further deceiving their wives. Another woman in Bombay echoed her sentiments, but added that earlier testing might have led her to be more careful with her health, thereby allowing her to remain asymptomatic for longer. A few women spoke about the traumatic wait between testing and diagnosis. One woman suggested that hastening the process would help relieve the “agony of waiting”.

The majority of the women in Edinburgh were diagnosed at a time in the mid-eighties when pre-test counselling was not very common. The majority of these women recalled the harsh and sometimes inhumane ways in which their diagnosis had been revealed to them. Many of them believed that this ill treatment had affected them psychologically, and had contributed to the grief they experienced on diagnosis. Several women recounted the inhumane treatment they received at the point of diagnosis, which included violation of their confidentiality and privacy, sarcastic and cruel remarks, and overt fear on the part of the medical providers.

Two women in Edinburgh who were tested in the late nineties painted a completely different picture of testing in Edinburgh. They both recalled the support they had received both before and after testing. One of these women explained that this counselling was the crucial first step in learning to live positively. Moreover, the time between getting tested and receiving the results was drastically shortened to a few hours, thus decreasing the agonising wait described by other women in Bombay and Edinburgh.

Women in both contexts generally served as the care providers and supporters of their partners and children when they became ill with AIDS. However, as this study demonstrates, that was not always the case for the women themselves, as partners predeceased or deserted them. Both Scotland (Sims and Moss 1991) and India (Bharat 1996) have cultures in which the extended family is strong, and the family generally provides support. In Bombay, some respondents received support from their families of origin, others from their cousins or neighbours. Only one woman said that she received support from a voluntary organisation working in the field of HIV/AIDS. Bombay has few organisations in the field that provide social support to women with HIV/AIDS. There is a growing need for more services of this nature. Some women spoke about the lack of and the need for financial support. Two women reported receiving financial support from a voluntary organisation that liaised with ARCON.

Women in Edinburgh also received support from their families. Additionally a large majority recollected the immense social support they received from the NGO in which this study was conducted: Solas. Women recalled the importance of the “Buddy Service” that provided them with emotional and practical support on a one-to-one basis. Many of the respondents in Edinburgh pointed out that the social support they had received had helped them to reshape their lives. One woman stressed the fact that this support allowed her overcome her isolation and still feel a part of society.

Two of the women who were involved in both use and peddling of drugs as well as in sex work, spoke about the opportunity a HIV/AIDS diagnosis had offered them to reshape their lives. They recalled how crucial the support they received from Solas and from social work services had been in moving away from their earlier life styles. They believed that the support they received on the methadone programme was also crucial in the rebuilding of their lives. In the light of these women’s experiences, there are implications for the ways in which NGO’s and social services could facilitate drug treatment and social support to women in the process of reconstructing their lives.

### Implications for Social Work Practice

This study provides an insight into how HIV/AIDS affects women from diverse cultures, with diverse life histories, and how the prevailing social realities of that culture impinge on their life experiences. It also explores the women’s subjective understanding of being positive, the ways that HIV changed their views of themselves, and the processes of personal change and development engendered by living with HIV/AIDS. Thus, it has important implications for social work practice which is rooted in democratic and humanistic traditions, and has an important role to play in helping those persons who are infected and affected by HIV/AIDS.

Social workers in India and Scotland work on the “front line” in dealing with social problems, including the many profound problems engendered by the HIV epidemic.



Irrespective of whether they are working at a medical or community level or at a larger political level as advocates, social work professionals have a responsibility to develop comprehensive knowledge and skills and to draw on any resource that might make a difference to persons living with HIV/AIDS.

Although the theoretical substantive teaching of social work in both contexts is similar, the way social work is practiced in India and in Scotland differs significantly. Social Work in India remains within the realm of non-governmental, voluntary or charitable organisations, and this is reflected in its perception as an altruistic and philanthropic profession. Hence social workers are viewed by the public as benevolent helpers and change agents.

The Government of India, through its Department of Social Welfare and Health, has legislated on social welfare policies and programmes; however there are no statutory powers attached and the public in general have few statutory rights to welfare services from the state. Most of the social welfare programmes across the country are carried out by non-governmental organizations, with or without financial support from the government. Their remit is limited to specific areas of social work and is constrained by lack of resources and the enormity of the need.

The lack of statutory social work legislation in India makes it impossible for the public to seek social welfare services from the government, and this is especially true in the case of persons living with HIV/AIDS, where statutory welfare programmes are limited and the only supports they can access are provided through non-governmental organisations. And here too, the support is generally in the areas of information, education, and counselling and not for treatment, services, or financial resources.

Social workers in Bombay typically work in hospitals, schools, industry, social welfare organisations such as orphanages, drug and alcohol treatment centres, and slum communities where developmental projects are being run. My respondents from Bombay had no previous contact with social work in any of these settings, nor did

the organisation ARCON, where I conducted my study, as it employed psychologists as counsellors. Clearly, the role of social work in this setting is quite different from that in Scotland.

Social Work in Scotland takes its root largely from the Social Work (Scotland) Act of 1968, where statutory powers were invested in the government and implemented through local authorities, thus guaranteeing welfare services to the public. Over the years, an array of social work policies and programmes have been developed which have helped shape the practice of social work in present day Scotland. Some of the recent Acts include the Community Care Act (Scotland) of 1990, the Children's Scotland Act (1995) and the Community Care and Health (Scotland) Act 2002. All these statutory policies impose on the government an obligation to provide welfare services when assessed as necessary. Thus, members of the public are guaranteed that they can seek assistance from the state when in need. However, the statutory nature of the services, gives the profession a negative image and often social workers are not viewed very kindly by the public.

Social workers in Scotland work in the social work departments of the local authorities and also in non-governmental voluntary organisations. Some of my respondents from Edinburgh, unlike those in Bombay, had previous contact with social work.

It can be seen that the two contexts of this study have quite different structures for the delivery of social work services and quite different understandings of what social work entails. Despite these differences, the many implications of the study can be applied to social work practice in both settings, albeit in somewhat different ways.

The findings and recommendations from this study also have implications for social work education. Social work has a need for informed graduates with insight into effective and humane ways of working with persons living with HIV/AIDS.

In this section I have sought to provide an insight into the implications of my study for social work practice. These implications are explored in two parts, first, the immediate implications emerging from the three-part model of change introduced in this study, and second, the implications emerging from the larger context of social work practice and HIV/AIDS at six levels of practice.

### **Practice Implications from the model of change**

Social workers require new models of practice if they are to intervene meaningfully with HIV positive persons and contribute effectively towards ameliorating the suffering that is rooted in the socio-cultural, economic and political realities of the HIV/AIDS epidemic. The three-part model of change introduced in this study has some interesting implications for the field. First, the notion of turning point is something that practitioners must understand and respect. The women in my study did indeed experience an important turning point in their lives, but it was not necessarily the advent of HIV that they saw as the turning point. Practitioners must not assume that a woman who is infected with HIV will see that as the most important factor in her life. They must pay attention to the losses and survival issues that are often the key experiences and key areas of need for these women.

Second, the notion of transition has important implications for practice. The period immediately after diagnosis was often a period of disorganization, anger, confusion, and hopelessness. Practitioners can be extremely helpful to women during this period, but they must understand that this is not the end point for the women, but rather part of the process of adapting to the overwhelming changes in their lives. Providing resources and encouragement at this time may have an important impact on the outcome for women facing the threats created by HIV and AIDS. The importance of recognizing the humanity of these women and allowing them to tell their stories has already been discussed. Perhaps these factors are most important during this key period of transition, when there is the opportunity to influence these women towards transformation and new meaning in their lives.

Finally, social workers must understand the notion of transformation and all that it implies. It is easy to become discouraged and to feel hopeless when trying to help women who seem to have so little in the way of resources or support. Understanding that transformation is possible, even for these women, is an important step towards supporting them. Providing these women with information about the process of change and adaptation, and with examples of the ways other women have transformed their lives, may be a useful step in encouraging transformation. Learning about the factors that work against transformation may also be helpful for social workers. With better understanding of how people can overcome extremely negative circumstances, social workers may be able to facilitate the conditions that bring about transformation.

### **Social Work Practice and HIV/AIDS: Implications on Six Levels**

While the change model presented in this study has a number of practice implications, one can also think about implications of the study that are relevant to the larger context of social work as a field. Social workers, in addition to being practitioners, also function as researchers, advocates, and advisors. This section will examine some implications of the study that can be understood on six different levels that reflect the varying ways that the field of social work can influence research and programming for those with HIV/AIDS.

#### **Empowerment of HIV positive women**

Social work is a profession that empowers and liberates individuals to enhance their well-being (The International Federation of Social Workers (IFSW) 2000). Thus this study has particular implications for the role of social work in improving the human condition of positive women who are vulnerable and oppressed in society, by focussing on their needs and empowering them.

**Giving a voice to the voiceless.** Qualitative studies that establish the voices of women living with HIV/AIDS are not very prominent in the literature on HIV/AIDS

in the field of social work in either of the contexts, but particularly in the context of India. By highlighting the voices of the HIV positive women, the study has important implications for social work, as it informs professionals in the words of the positive women themselves, such that they are assisted in the task of empowering women to live with HIV/AIDS.

Moreover, the study has particularly important implications for practice because it provides a platform where the voices of voiceless positive women are communicated, such that they have an impact on shaping policy and program responses to this complex phenomenon. These voices are critical for social workers in their struggle against societal barriers of stigma, discrimination, and human rights inequities in the access to life-saving treatment.

**Providing hope, meaning and enhancing resilience.** Promoting hope, meaning and resilience in the lives of HIV positive women, are vital steps in the process of empowering women. The accounts of other women living with HIV/AIDS provide hope, insight, and meaning for persons with HIV/AIDS, their families, friends, and other persons interested in the subject, because they highlight the profound paradox of being HIV positive, the irony of having hope destroyed while at the same time becoming ever more dependent upon it (Kain 1996). The women's accounts are ultimately empowering because they reveal how acceptance and hope sustained them in their struggle with HIV/AIDS and gave them the ability to somehow emerge as victors. Despite the devastation, pain, and hopelessness, some of these HIV positive women found a way to carry on, to look towards the future, and to find meaning in their lives.

Moreover, the insights provided from the accounts of the women in my study could enable practitioners to enhance the resilience of HIV positive persons, by searching with them and helping them to identify the strengths which they bring to their situation and to create an alternative story that includes a realistic component of hope and meaning in the face of the many adversities of living with HIV or AIDS.

**Minimization of violence.** The lives of several women in Bombay and Edinburgh reflected the varied physical, emotional, and mental abuse and violence they experienced. Minimising violence in the lives of women is significant for social work intervention with women in varied fields, but particularly crucial in the lives of women with HIV/AIDS. Social workers need to develop an empathetic grasp of the role of abuse and violence in HIV/AIDS infection, as demonstrated in this study, so that they can help to combat the conditions that expose women to risk.

**Providing support.** The accounts of the women in both contexts reflect the crucial need for support, in the face of the stigmatisation and discrimination they experienced. This has differing implications for social work practice in the two contexts. In the context of India, social workers need to recognise and encourage connectedness to family of origin as a means of coping. Moreover, efforts to form self-help groups and women's groups in clinics, community settings or at the non-governmental organisation level, where positive women receive support and are able to provide it to other women living with HIV/AIDS, are very important steps forward. In the context of Scotland, social support offered by existing "buddy services", women's groups and other supportive activities that provide emotional or tangible support need to be fostered and boosted.

### **Insight and increased sensitivity**

The study provides a deep insight into varied aspects of the lives of women living with HIV/AIDS in two cultural contexts, and into researching their lives. This understanding is particularly important in the process of developing sensitivity in social work professionals.

**Power of telling their story.** This finding provides an important insight into the aspect of communication in social work practice. For the positive women in my research, making sense of their complicated and often tragic stories seems to have been a healing and ultimately encouraging experience. The process of telling a



coherent and meaningful account of their lives reflected their resilience in the face of adversity. The power of telling their story lies in the meaning of the experience, and the very act of telling one's story seemed to be a transforming experience. Their stories are also empowering for other women living with HIV/AIDS, because it helps them to know they are not alone. Narrating one's life story could be used as a valuable therapeutic tool for bringing about change in the lives of HIV/AIDS infected and affected individuals. Social work practitioners, researchers, and policy-makers need to have an awareness of this phenomenon. It holds potential as an avenue for providing assistance to those with HIV/AIDS, and also as an area that needs to be better understood.

**Linear Accounts.** Less common with regard to the findings from a qualitative study, the findings in this study are presented in a linear progression, using the three stages of the illness: pre-diagnosis stage, diagnosis and post-diagnosis that marks the path of the women's stories of living with HIV/AIDS and the elements of change in their lives: the turning points, transitions and transformations. The study thus suggests the value of a developmental perspective, which may prove useful in further studies and in designing interventions for women as they cope with diagnosis and its aftermath.

**Thoughts and feelings of women.** This study aimed to document the thoughts and feelings of women living with HIV/AIDS, from their own perspective. These women, many of whom were disenfranchised and ignored, had a unique and valuable perspective on living with the illness, which has important implications for social work intervention and practice in the field of HIV/AIDS. Interventions, research, and policy making that foster efforts to help women express themselves and to use their voices on behalf of others may prove valuable for the field of social work on several levels.

**Transformational impact of treating clients as human beings with the ethic of dignity, self-worth and compassion.** Many women in the study referred to HIV/AIDS "making" them into better human beings and giving them a purpose to live. They alluded to the dignity and respect that they were given, often for the first time, for some after years of being stigmatised, as in the case of the sex workers in

Edinburgh. This finding is particularly relevant to social work practice, which values the inherent worth, dignity and uniqueness of individuals (CCETSW 1995) and aims to afford its clients with the respect and dignity they deserve. Social workers should examine this phenomenon and work to incorporate it into research and policy making. It would particularly valuable for them to examine the transformational impact of treating clients with the ethic of dignity, self-worth, and compassion, as a powerful force of empowering women through emotional healing and self-transformation.

## **Practical**

The study highlights the need for social work intervention in the practical areas of testing, treatment, and counselling and supportive services for HIV positive persons. The social work intervention at this level differs significantly in the two contexts, because of the differences in the availability of resources in developing and developed countries.

**Testing and Treatment.** This study has differential implications for social work in the areas of testing and treatment for HIV positive women in Bombay and Edinburgh.

Women from both contexts suggested that pre- and post-test counselling was an important factor in the acceptance of an HIV/AIDS diagnosis. The accounts of most of the women who received this counselling revealed that this counselling was invaluable in helping them to prepare and accept the HIV/AIDS diagnosis. Conversely, the accounts of many women in Edinburgh who were tested in the early 1980s and did not receive any counselling revealed that the lack of this vital intervention retarded their process of accepting and learning to live with their HIV/AIDS diagnosis. Moreover, it is important for social workers to reflect on the value of receiving test results within a few hours (as was the case with a few women from Edinburgh who were tested in the late 1990s) thus decreasing the agonising wait described by some of the other women in Bombay and Edinburgh.

The study revealed the harsh reality of the availability of treatment. Anti-retroviral treatment is available in both India and Scotland; however, it was not available to my respondents in Bombay. They were unable to share in the scientific advances that other wealthier women in India, or women in Edinburgh, who received it as part of statutory health services, were able to benefit from. Social workers in India have a crucial role in advocating on behalf of persons living with HIV/AIDS, with pharmaceutical companies and political parties, to establish a new system of free anti-retroviral treatment. This campaign should be guided by the quest to ameliorate the preventable suffering caused by HIV/AIDS.

Social workers in both contexts need to be aware of the many efforts being made to reduce the impact of the suffering that entwines the HIV/AIDS epidemic, in particular the Global Fund to Fight AIDS, Tuberculosis and Malaria, established in 2001. These examples will serve as a tangible hope for social workers (in both contexts, but particularly in the context of India) in their struggles for and intervention with persons infected or affected with HIV/AIDS.

**Counselling and Supportive services:** The accounts of some women in Edinburgh reflected that support workers who were trained in the role of being helpers, who listened, and whose approach was direct and genuine were truly useful. Women in Bombay spoke about the caring and understanding approach of the counsellors that helped them to articulate what they really wanted to say. The importance of counselling and supportive services is an essential element of social work practice. However, due to limited resources in both settings, but especially in the context of India, these services are limited.

The accounts of women in Bombay reflect the need for provision of personal social services to people living with HIV/AIDS in India. Social work intervention should focus on the establishment of new social institutions, such as community welfare centres, that focus on the universal satisfaction of the basic human needs of food, clothing and shelter.

The accounts of a few women in Edinburgh reflect that the support they received on the methadone programme was a crucial element in the process of rebuilding of their lives. These experiences have particular relevance to social work practice; it has implications for the ways in which NGO's could facilitate drug treatment and social support to women in the process of reconstructing their lives.

### **Education and Awareness**

This study highlighted the reality that the vulnerability of women to HIV/AIDS is enhanced by factors such as poverty, economic dependence on men, lack of access to education and health facilities, abuse and violence, myths and beliefs that disempower them, and conditions that coerce them into selling sex for survival or to support a drug dependency. It also highlighted the stigma and discrimination experienced by women in both contexts, but particularly in Bombay. Thus, education and awareness are crucial components of social work intervention with HIV positive women and men, which could be implemented through developmental programmes and community education.

**Developmental Programmes for women.** Social workers need to create developmental programmes that empower women (both HIV positive and negative women) through education, awareness, information, and support. With the aim of "conscientising" them such that they can challenge the structures of oppression that dehumanise them and make them vulnerable to HIV/AIDS. There is also a critical need for social work intervention in the education of men in both contexts, but particularly in the context of India. Men need to understand the risks they expose themselves and their families to when they engage in risky behaviours such as unprotected sex, drug use, and alcohol abuse.

**Community Education programmes to prevent stigma and discrimination.** The women's accounts from both contexts revealed the great need for education of the general public. Social work can play a major role in changing the perceptions of society through community education programmes that enhance the awareness of

individuals in the community regarding the stigma and discrimination they experience or perpetrate. Education and awareness of the general is crucial because of the uniquely stigmatising effect of HIV/AIDS, in the context of both developing and developed nations. This study revealed a particular need in this area, because the stigma experienced by women reduced their ability to obtain treatment and heightened the trauma of their diagnoses. In the context of India, social work needs to pay particular focus to the severe stigma, shame, and blame women experience from their families of marriage. Similarly, medical professionals also need to be sensitised to these issues while working with HIV positive persons.

**Social “safety net” for HIV-infected.** This study also revealed a great need for some sort of “safety net” or “last resort” for HIV/AIDS-affected persons who lose their homes and livelihoods because of HIV/AIDS. Social workers can be instrumental in developing programmes to provide basic needs such as shelter, medical care, and food for individuals in this situation.

## **Advocacy**

Social workers have a role to play as advocates on behalf of persons living with HIV/AIDS, through the creation of gender sensitive policy and programme environments, the promotion of human rights and the promotion of women’s ability to protect themselves. Social workers stand in a unique position in this regard, because of their education about the larger social systems that impinge on people with HIV/AIDS, as well as their ability to connect with people affected by HIV/AIDS on a personal level.

**Creation of gender sensitive policies and programme environments.** The insights gained from this study reveal the importance of social work intervention in the creation of gender sensitive policies and programme environments for women and their children living with HIV/AIDS in both contexts. Social workers can and should advocate for policies about gender relations that will make the lives of women a little better.

**Promotion of internationally guaranteed human rights.** Social work has an obligation to uphold the fundamental human rights of individuals. This study revealed that women in the context of India (and to a much smaller extent in Scotland too) were deprived of their right to health as reflected in many instances in their accounts: inability to buy nutritious food, inability to buy medicines, inability to protect themselves sexually from being re-infected by their partners, lack of support services, and the lack of social controls over cruel structures of oppression and misinformation. In their role as advocates, social workers can draw attention to these inequities and promote fundamental changes that will ensure the rights of women in all settings.

**Promotion of women's ability to protect themselves.** This study reveals the harsh reality of the power differential that exists between men and women in socially and economically deprived groups in both contexts. As discussed in earlier chapters, women have very limited power to assert their rights to avoid the behaviours that can lead to infection with HIV/AIDS. The insights gained from the study in relation to how histories of individual, social and structural vulnerability contribute to women's greater vulnerability to HIV/AIDS, are particularly relevant to social work practitioners who have a crucial role in reducing the vulnerability of women through advocacy.

### **Evidence based Practice**

Much of the knowledge base in relation to working with HIV positive persons emanates from the fields of medicine, sociology, and psychology. There appears to be a limited contribution to HIV/AIDS literature from experienced social work practitioners. It is crucial that the practice wisdom of social workers be documented for increased practitioner knowledge and informed social work education.

As discussed at some length later in this chapter, in the section on implications for future research, this study provides a springboard for further research in a number of



areas. This research can help to expand the knowledge base of social work and create a body of literature to inform future social work practice in the field of HIV/AIDS.

In conclusion, the study reflects that the HIV/AIDS epidemic thrives among tragic human conditions that are enhanced by poverty, abuse, violence, prejudice, and ignorance. The women's physiological risk of HIV/AIDS infection is compounded by low education, poor employment opportunities, and socio-cultural norms and structures of oppression that discriminate against people because of their social class or the activities they may engage in, such as sex work and drug use (UNAIDS 1999). These are the very realities that social workers need to address, with a special emphasis on their intervention with women and children living with HIV/AIDS, because they are a section of society's most vulnerable and oppressed around the world. Social workers, in their multifaceted roles as counsellors, educators, and advocates, have many important contributions to make to the worldwide struggle with HIV/AIDS.

### Implications for Future Research

This research provides an insight into the life experiences of positive women, but it does not fully explore the phenomenon. More structured and formalized research is needed to address the many questions that can be generated by a study of this type. Indeed, an important function of an exploratory study is to generate questions and hypotheses that can be examined using more formal techniques. The current study has yielded many such questions, as will be described below. This study merely touches upon the lives of HIV positive women in the two contexts of a developing and a developed nation, and suggests important questions to explore about their life experiences, turning points, transitions, and transformations.

It is my hope that this study provides a springboard for further studies in relation to lives infected and affected by HIV/AIDS. This study can be used as a source of hypotheses for future research in relation to the spectrum of experiences that first, lead to HIV infection; second, are results of an HIV/AIDS diagnosis; and third,

facilitate persons to live positively with HIV/AIDS and help in their long-term survival with HIV/AIDS.

A number of the women in the present study described reactions that suggest they were experiencing symptoms of PTSD prior to their diagnoses. Many of these women had undergone significant traumatic experiences, such as rape, death of a partner or child, or abuse, and their reported reactions mirror many of the acknowledged symptoms of PTSD, such as numbing of emotions, re-experiencing of the trauma via intrusive thoughts, and sleep disturbance (Kaplan and Saddock, 1985). It would be useful to explore the influence that these symptoms have on self care of these women, and in particular on self-protective behaviours. Does the experience of severe trauma and the resulting symptomology increase a woman's risk for contracting HIV/AIDS? If so, is this a result of diminished self-protective behaviour or of some other mechanism?

The accounts of the women in Bombay reflected the prevalent myths and beliefs about the spread and cure of HIV/AIDS. The lives of some respondents were shaped and altered by the dangerous myth that marrying a virgin cures HIV/AIDS (Radhakrishna et al 1997, Tinker et al. 2000, Larson and Narain 2001). Their accounts also revealed the significance of *karma* in the Indian psyche. It would be helpful to explore the role of prevalent myths and beliefs in the spread of HIV/AIDS. How widespread the myth that having sex with a virgin cures HIV/AIDS? Moreover, does a belief in *karma* play a role by impacting self-protective behaviours or by influencing the grief process once a diagnosis has been made?

The lives of several women in Bombay and Edinburgh reflected the varied physical, emotional, and mental abuse and violence they experienced. Violence against women is believed to be a significant contributor to the spread of HIV/AIDS (Gordon and Crehan 1999, Brundtland 2000, UNFPA-OBP 2000). It would be of use to look at the role of abuse and violence in HIV/AIDS infection: are persons who experience abuse and violence are more susceptible to HIV/AIDS than other women from similar socio-economic strata that have not suffered abuse?

Other research implications reflect the process of receiving and adjusting to a positive HIV diagnosis. The accounts of the women in both Bombay and Edinburgh revealed that anger was the most common reaction to a HIV/AIDS diagnosis. Speaking about her own personal experience of being debilitated by a series of strokes, Kubler-Ross (1997a) reiterates that she only experienced the third stage of anger (Kubler-Ross 1969). It would be meaningful to explore the prevalence of the anger response to a HIV/AIDS diagnosis. It would also be helpful to examine the effects of anger. Does it serve to energise women? Is it helpful in moving them to seek better treatment, to assert their rights, or to make lifestyle changes for the better?

In contrast, the accounts of a few women in Edinburgh reflected the notion that discovering one's HIV/AIDS status brought a sense of order and meaning to lives that were previously chaotic. It would be valuable to develop a deeper understanding of this phenomenon. Is this a subjective perception, or is there a tangible link between the diagnosis of a terminal illness and the need to bring order in one's life?

The family seemed to play a crucial role in the lives of the majority of the respondents. The family of origin, in particular was found to provide support to women in both contexts. It would be of use to explore the role of the family of origin in the long-term adjustment and survival with HIV/AIDS. Additionally, it would be useful to explore the role of formal and informal support in the long-term adjustment and survival with HIV/AIDS. It may be possible to develop strategies that help enlist families and extended support systems to assist people as they adjust to the HIV diagnosis and its aftermath.

Another possible area of investigation concerns the role of individual differences in responding to dramatic turning points. Some of the women in my study were able to transform their lives for the better, despite very limited resources and a long history of maltreatment and hopelessness. Other women seemed to respond to the situation by becoming more hopeless and helpless. It would be helpful to have a better understanding of the characteristics that enable a person to adapt creatively to

change, whether they are personality traits or aspects of the person's environment or support system.

One of the somewhat unexpected finding of this study was the positive effect that participating in the study had on many respondents. For these women, telling their story to a caring listener had a valuable impact. A series of formal studies could examine the impact and power of telling one's story and having it recognized as valuable and meaningful. Perhaps narrating one's life story could be used as a valuable therapeutic tool for bringing about change in the lives of HIV/AIDS infected and affected individuals.

Finally, several women in the study referred to HIV/AIDS transforming them into better human beings and giving them a purpose to live. They alluded to the dignity and respect that they were given, often for the first time, for some after years of being stigmatised, as in the case of the sex workers in Edinburgh. It would very valuable for social workers and other professionals in the caring professions to study the transformational impact of treating clients as human beings with the ethic of dignity, self-worth, and compassion. This compassion, experienced by many professionals as a moral imperative (Kain 1996) may also be a powerful force in promoting emotional healing and self-transformation among individuals who have never before experienced any recognition of their human worth.

### Limitations of the Study

The study is not without its limitations, and although the findings provide an understanding of the life experiences of the respondents, they are not indicative of the experiences of all positive women in Bombay and Edinburgh. It is important to note that my findings could have differed significantly had my study population of positive women varied. That is, had I spoken to women in Bombay who were receiving anti-retroviral therapy, or women who were all involved in sex work in Bombay or Edinburgh, or women who were injecting drug users in Bombay and

Edinburgh, or any different stratum of society, I might have arrived at different conclusions.

This qualitative study did not incorporate the controls that are necessary for more definitive findings, because it was focused on exploring the material without imposing any prior expectations on the findings it generated. For the same reason, it did not utilise any objective measures for constructs that have been introduced, such as stress, trauma, and vulnerability. Also, because of the unique features of the populations studied, the findings may not be generalizable to other populations. However, as this study was qualitative and exploratory in nature, it sought to discover (Padgett 1998) and celebrate the uniqueness of human experience (Donmoyer 1990). The study's greatest value may lie in the depth of exploration given to the stories of these women, as well as the many important questions raised by these stories.

Finally, this study was based on recollections of past events, or the use of retrospective data. Relying on memory could create potential problems, such as being unable to recollect certain events, alteration of memories to preserve a positive self-image, and mistakenly recalling the timing of an event (Singleton et al 1993). Qualitative studies may come or appear to come nearer to human reality, however, only as filtered through the observers' fallible memory (Scheff 1997). Because of the nature of the issues being studied and the profound effect it had on their lives, I believe that the women's recollections used in my study are reasonably free of these problems. It should also be noted that many aspects of this study required a retrospective approach, since the participants were less likely to be located or to be able to discuss their situations at earlier points in their lives.

### Some Final Observations

In the course of my study, I had the privilege of listening and understanding the stories of twenty-seven women living with HIV/AIDS. It is my hope that this study will provide a voice for women who had been "robbed of their voices long before

HIV appeared to further complicate their lives” (Farmer 1996, p.7). Their voices are compelling because they narrate the stories of the journeys they made with HIV/AIDS. Their voices are persuasive because, for many of the women, it was the first time (and for some, perhaps the last) they shared their thoughts, feelings and experiences. Their voices and words are powerful because the process of telling and sharing is one during which they made sense out of their life experiences. Most important, their voices are a crucial outcome of my study, because in a small, yet significant way, they bear testimony to the lives of positive women, who in the face of numerous struggles and challenges continue to hold on to hope, creating strategies to live with HIV/AIDS. This growth occurred irrespective of whether they lived in Bombay or Edinburgh. Finally, their voices are critical if the barriers of stigma, discrimination, and denial are to be overcome and the glaring human rights inequities in the access to life-saving treatment (UNAIDS 2002d) is to be bridged.

The majority of the women’s accounts reflect resilience in the face of adversity. S. Vanistendael (personal communication, January 27, 1998) suggests that resilience is a practical and inspirational concept that describes “the capacity to resist destruction, i.e., for a person to protect his/her integrity under difficult circumstances”; and, “the capacity for positive construction in spite of difficult circumstances” (Vanistendael 1994, p.4). As demonstrated earlier, majority of the respondents in both Bombay and Edinburgh experienced tremendous adversity in their lives, both before and after they were diagnosed. Their accounts reveal their struggles and their determination to live with the physical, social and emotional hardships they encountered. They also illustrate how women tried to reshape their lives in the face of illness, loss, HIV/AIDS, stigma, and shame, and for some poverty and deprivation as well. The accounts of a large number of women reveal how they made positive changes in their lives. However, some accounts reveal that before women could make positive constructions, they underwent periods of extreme pain, where they tried in fact to self-destruct. One woman in Edinburgh had a nervous break down for almost a year, while another woman in Edinburgh, just a teenager then, took to abusing drugs, with the hope that she would kill herself.



This study also emphasizes the fact that although epidemiologically the HIV/AIDS pandemic differed in Bombay and Edinburgh, and the treatments available varied substantially, as did the cultures and society the women belonged to, the impact of HIV/AIDS on the lives of individual women was essentially the same, because they shared the common bond of gender. My study upholds Bury's (1992, p.7) assertion that:

***“The impact of the epidemic on communities in different parts of the world may vary but the impact of HIV infection and AIDS on the individual woman is fundamentally the same.”***

Another observation concerns the growing reality of hope for impoverished people who are afflicted with HIV/AIDS. The HIV/AIDS epidemic has motivated new forms of mobilisation in countries all over the world, such as community-based support networks and social rights groups that advocate treatment, protection of human rights, and enhancement of socio-economic conditions. One remarkable example of such mobilisation is the initiative taken by the Brazilian government to offer to transfer, at no cost, the technology required to manufacture antiretroviral medicines (Teixiera 2001). Saag (2002) suggests that Brazil's actions illustrate the kind of supranational partnership essential in the fight against HIV/AIDS. Another example is the Haiti model, developed by Farmer. This model illustrates that multi-dimensional intervention and provision of an uninterrupted drug supply in an area of great poverty, unemployment, hunger, and other deprivations can succeed through the leadership of one visionary individual (O'Grady et al. 2002). In these situations “people have chosen to act not on the basis of fear and denial, but of compassion and solidarity” (UNAIDS 2002e, p. 59). As Scott (1997, p.49) reminds us, “at the entrance of the twenty-first century, a door is waiting for us to open as we gather as individuating souls to act in new ways”. For some of my respondents these changes may be too distant or too late, but in historical terms, the national and global responses that HIV/AIDS is bringing are “a little short of revolutionary” (UNAIDS 2002f, p. 186).

It is encouraging that two decades after the world first heard of a “curious disease that attacked the immune system” in June 1981 (in a report published by the Centre for Disease Control), the global resolve to struggle against HIV/AIDS has intensified (UNAIDS 2002g) in the form of the Global Fund to Fight AIDS, Tuberculosis and Malaria, established in 2001 and operating since January 2002. The Fund aims to mitigate the impact caused by these illnesses. It also aims to contribute to poverty reduction as part of the Millennium Development Goals, which focus on reversing the global spread of AIDS by 2015, halving global poverty; ensuring primary school education for all; promoting gender equality and empowering women; improving maternal health; and reducing child mortality rates. This total package is integral in turning the tide against HIV/AIDS (UNAIDS 2002h). Sachs (2002) argues that this Fund is the “most promising single instrument” in the fight against HIV/AIDS.

Finally, this study reflects vulnerability and hopefulness on a more individual level. This study of women in vastly different settings points to the ways in which they are disproportionately affected by the HIV/AIDS epidemic, but also to the ways in which they have found hope and meaning. Beyond their vulnerabilities, many of these women shared an almost paradoxical sense of hope. For some, hope came in the form of expectations for help from medical advances. For others, hope surrounded smaller, more intimate issues, such as living to see a child grow up, or finding a way to improve daily living conditions. Despite devastation, pain, and hopelessness, these women found a way to carry on, to look towards the future, and to find meaning in their lives. Andrea’s (E. 18) words reflect these ideas, and provide a fitting ending for my study:

*“I just feel thankful that I am here today. I do think I have a future ... I feel that with combination therapy there is hope for people with HIV and AIDS. Hope gives me the strength to carry on ...”*

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## Appendices

### APPENDIX A

#### BACKGROUND INFORMATION ON HIV/AIDS

##### Epidemiological Background

Epidemiology is the scientific study of an epidemic or a wide spread occurrence of a disease (Collins Dictionary 2000). It is the study of the distribution and determinants of disease within and between different groups of people. It aims to identify the frequency with which particular diseases occur as well as the characteristics of those who are affected (Barker and Rose 1984).

##### Definition of the terms HIV and AIDS

AIDS is not a disease but a collection of seventy or more conditions, which result from the damage done to the immune system and other parts of the body as a result of infection by the HIV. Therefore, it is more accurately referred to as a "syndrome": a collection of various symptoms, infections, and conditions (Thomas 1995).

The Panos Dossier (1992) defines the terms HIV and AIDS as follows:

*AIDS (Acquired Immune Deficiency Syndrome) is the name given to the fatal clinical condition that results from long-term infection by HIV (Human Immuno Deficiency Virus). HIV progressively damages the body's immune defence system, preventing the body from protecting itself against infections that it would otherwise render harmless. Over time HIV weakens the immune system to the extent that several opportunistic infections are present at once; death is not caused directly by HIV but by one or more of these infections (p.2).*

##### Incidence

At the end of 2001, an estimated 40 million people were thought to be living with HIV/AIDS, of which 37.1 million were adults, of whom 18.5 million were women. At the end of 2001, the number of people newly infected with HIV was estimated to be 4.2 million adults, of whom 2 million were women. There were 3 million people who died of AIDS in 2001, of whom 1.1 million were women (UNAIDS 2002a). The HIV/AIDS epidemic has spread throughout the world's population, including over 190 countries on every continent of the world (Mertens and Low-Beer 1996).

The HIV/AIDS epidemic continues to spread, undermining and reversing gains of development and intensifying poverty. Over 36 million people are living with

HIV/AIDS and the vast majority (95%) lives in the developing countries (The Population Council and International Family Health 2001). The HIV/AIDS epidemic has proved that we live in a truly global village. The rapid changes that are taking place in the world today have a profound impact on our lives: what happens in one place affects people all over the world (Rafei 2001).

Globally, India has the second highest estimated number of infections, next only to South Africa (Larson and Narain 2001). India is proving to be a fertile ground for the spreading of deadly HIV/AIDS, given its poor healthcare system, virtual lack of public hygiene, and poor literacy rate (Jit 1999). The epidemic rages virtually out of control in parts of India, because access to antiretroviral therapy is unaffordable except by a tiny percent of persons (WHO 1997).

In contrast, in the UK new treatments have slowed the progression of HIV to AIDS, and from AIDS to death. As a result, AIDS cases and deaths have dropped dramatically in the UK, and more people with HIV are living healthier and longer lives (THT 2002). However, despite its success in containing and treating HIV/AIDS, Britain has, in the year 2001, recorded its highest annual HIV/AIDS infection increase (14 per cent) since the epidemic began (Braid 2001).

### **Natural History of HIV/AIDS**

HIV is transmitted through sexual intercourse, infected blood and blood products, infected hypodermic needles, or through placental transfer to a foetus. HIV infection is believed to be life-long, and the presence of antibodies against HIV ('a positive HIV test' or being 'HIV positive') is assumed to mean the virus is present. HIV primarily infects cells of the immune system. In particular, the T4 (also called CD4) lymphocytes are infected. An individual is considered to have AIDS if they have a T4 cell count of less than 200 (Moyle, 1997). In India however, according to NACO (1996), Clinical AIDS in an adult is defined as an individual who has been identified as meeting two criteria: first, two positive tests for HIV infection by the ERS test (ELISA/RAPID/SIMPLE); second, the presence of any one of following criteria:

- a) Significant weight loss (greater than 10% of body weight) within last one month or cachexia (general poor health, weakness and malnutrition) not known to be due to a condition other than HIV infection;  
AND  
Chronic diarrhoea (intermittent or continuous) greater than 1 month duration or prolonged fever (intermittent or continuous) greater than 1 month duration.
- b) Tuberculosis: Extensive pulmonary, disseminated, or extra-pulmonary tuberculosis.
- c) Neurological impairment preventing independent daily activities, not known to be due to the conditions unrelated to HIV infection (e.g. trauma).
- d) Candidiasis (yeast infection) of the oesophagus diagnosable by oral candidiasis with odynophagia (painful swallowing).



- e) Clinically diagnosed life-threatening or recurrent episodes of pneumonia, with or without etiological confirmation.
- f) Kaposi Sarcoma.
- g) Other conditions, such as Streptococcal meningitis, Neuro-Toxoplasmosis, CMV retinitis, *Pneumocystis carinii*, Recurrent Herpes Zoster or multi-dermatomal herpes infection or disseminated molluscum.

The T4 cells are important in coordinating the immune response, and as they eventually decline in number the HIV positive person is left prone to certain infections, known as 'opportunistic infections', and cancers. At this stage the person was once said to have an AIDS-related complex (ARC). This term is now outdated, and 'Symptomatic HIV infection' is now the accepted term for this stage of the illness (Singh 1994), or 'active HIV infection' (Gaitley et al. 1993). When certain specific opportunistic infections or cancers develop, a person is considered to have AIDS.

The natural history of the virus has been classified in different ways by different authors. Thomas et al. (1997) enumerate five stages in the development of HIV infection based on World Health Organisation (WHO) and the Centres for Disease Control and Prevention's (CDC) 'case definition' of AIDS. The five stages are:

- (i) Initial HIV infection also referred to as "sero-conversion illness".
- (ii) PGL (Persistently enlarged lymph glands).
- (iii) ARC (AIDS Related Complex) where the AIDS virus has considerably damaged the immune system.
- (iv) AIDS: where the immune system collapses and major life-threatening infections enter the body.
- (v) AIDS Dementia: when the AIDS virus passes through the blood brain barrier and damages the brain cells, causing confusion, memory loss, premature senility, and incontinence.

However, many scientists suggest that the progress of HIV should not be viewed as a definite cycle of events (Sims and Moss 1991; Pavri 1992; Gaitley et al. 1993; Singh 1994). According to them there are four key elements to the clinical sequelae of HIV infection:

- (i) 'Acute HIV Infection' or 'Acute Sero-conversion Illness': between two weeks and six months of exposure to the virus, a person may experience a 'flu-like' illness, similar to glandular fever, with symptoms of aching, rashes, and swollen lymph glands. At this stage individuals produce antibodies to HIV. According to Singh (1994) the first clear manifestation of the virus is the sero-conversion illness, which may often go undetected. Although the body produces the antibodies, the presence in the blood stream may not occur for at least three months. The period is known as the 'window period', because the blood test will not reliably be able to confirm or deny the presence of HIV.



- (ii) 'Asymptomatic HIV Infection' or 'Antibody Positive': Individuals may remain asymptomatic at this stage, but they can infect others.
- (iii) Symptomatic HIV Infection or Antibody Positive: As the infection progresses the CD4 lymphocyte count drops and person develops signs of ill health. Symptoms of this stage include fatigue, anorexia, weight loss, persistent lymphadenopathy and diarrhoea, skin infections, candidiasis, herpes simplex and zoster infection etc. At this stage the CD4 count continues to decline and antigen levels rise.
- (iv) AIDS or Chronic HIV: These terms are used interchangeably. AIDS is diagnosed when one or more condition develop which are considered by the CDC to be 'AIDS defining'. Persons with AIDS have the most seriously impaired immune systems, and thus allow infections and cancers to proliferate. An individual may still manage to enjoy life at this stage.

The term incubation period refers to the time between infection with HIV and the development of an AIDS defining condition. The exact time limits of the incubation period for AIDS are not known. It is estimated that the incubation period ranges from 5 months to 15 years or more (Thomas 1995; Thomas et al 1997).

HIV belongs to the family of viruses, called the retroviruses, which are made of RNA (a precursor of DNA). HIV is a lentivirus, that is, a slow virus. There are 10 known sub-types of the HIV virus named from A to J. The most commonly found strain in India is the HIV-C, (Fox, 1999) whereas in the UK is HIV-B (Fox, 1999). The HIV virus has the ability to enter a cell without initially doing too much damage to it. The modus operandi of the HIV virus involves integration with the CD4 molecules that lie on the surface of a class of white blood cells called the T4 lymphocytes (also called the 'helper cells'). Next, the virus penetrates the gene. Having successfully accomplished the task, the HIV then 'hijacks' the gene and uses it for its own replication. The virus operates in the presence of an enzyme called "reverse transcriptase" (because, it does not follow the usual genetic information flow from DNA to RNA, rather it writes and transcribes backwards). In the course of this process, the 'helper cells' cannot perform their function of producing antibodies to a disease. And so the HIV continues to attack the cells that stimulate the immune system, thus rendering the body unfit to fight infection and eventually bringing death (Moyle 1997; Thomas 1995; Pratt 1991).

### **Modes of Transmission**

HIV is spread by sexual contact with an infected person, or by sharing needles and/or syringes, (mainly for injecting drugs of abuse) with someone who is infected. Less commonly, and now fairly infrequently in countries where blood is screened for HIV antibodies, it is also spread through transfusions of infected blood or blood clotting factors. Babies born to HIV-infected women may become infected before or during birth or through breast-feeding after birth (CDC 2002).

In India the predominant mode of transmission is heterosexual contact. HIV/AIDS infection in India is currently concentrated among poor, marginalized groups, including sex workers and truck drivers. The respondents in my study belonged to traditional cultures that held strong religious beliefs in the sanctity of marriage and fidelity. Even when they were told the modes of HIV infection, these women were unable to relate to the risk behaviours. Women who believe they are in a monogamous relationship do not see a correlation between their lives and the lives of an at-risk individual (Land 1994). However, the spread to monogamous, married women is clearly acute in India (Edmundson and Robinson 1999). HIV/AIDS is spreading among young, monogamous married women, who get infected by their only sex partners, their husbands (Quinn 1996).

The sex trade in India is very profitable; however, the women involved are paid paltry sums and have little or no freedom to move out of the trade. Burns (1996) suggests that the relationship between poverty, prostitution, and HIV/AIDS is overwhelming. Exchanging sex for money is an extremely high-risk behaviour, but it is continually practiced, sometimes out of ignorance but almost always out of need. Such cultural and societal factors amplify the vulnerability of women to HIV/AIDS.

McDonald (1992) argues that while prostitution is illegal in India it takes little effort to find a working prostitute. In rural areas, whole villages are often devoted to prostitution. These areas are usually on the routes of the hundreds of trucks that drive goods all around the country. Often times, the people inhabiting these villages and exchanging sex for money know nothing about HIV/AIDS (McDonald 1992; Pais 1996). Some women, driven by extreme poverty, migrate from rural areas to urban cities to work as prostitutes, and it is there that the problem is most severe (Burns 1996; Narain et al. 1994).

Indian truck drivers have emerged as key element in the transmission of the HIV (Burns 1996; Mane and Maitra 1992; McDonald 1992; Narain et al. 1994). These drivers often have low socio-economic and educational levels, move along the countries 20,000 miles of truck routes, and stay away from home for several weeks at a time. Burns (1996) notes that when on the road, the truck drivers stop at many villages, some of which are completely devoted to prostitution. In addition to having sex several times a day with known prostitutes, truckers rarely use condoms. Once they are infected, truck drivers become participants in the spread of the disease, bringing it home to their wives and sometimes to their unborn children (Burns 1996; McDonald 1992; Narain et al. 1994). Often the infection travels from big cities to towns and villages, where the majority of Indians live. Truck drivers seem to be the key to the spread of the disease to both rural areas and the general population.

HIV/AIDS appear to be moving into the homes of Indians in low-risk groups—the general population (Burns 1996; Mane and Maitra 1992; Pais 1996). The disease often travels with men who live without their families for a period of time (usually for their work) and who frequent sex workers. These men bring the disease home to their wives, individuals who would otherwise be at very low risk for contracting the disease. In Bombay, surveys have begun to show an incidence of HIV infection among housewives who have only had sex with one partner - their husband.

Until the beginning of this century, infected blood was a major means of HIV transmission in India. As voluntary blood donation is difficult to obtain for cultural reasons, professional blood donors donate up to 50% of the blood required in the country (Burns 1996; Narain et al. 1994; Pais 1996). Surveys show that these blood donors are usually poor, illiterate, single, migrant, or unemployed men who engage in sex work (Burns 1996; Pais, 1996). They get infected either through their frequent contact with sex workers or from contaminated needles used when donating blood (Imam 1992). However, strict laws and rules have been further revised in accordance with a recent Supreme Court judgment, which provides mandatory licensing of blood banks, bans professional blood donation and sets strict guidelines for holding of blood donation camps. The blood banks are now required to acquire a manufacturing license to provide services (NACO 2002).

According to the Public Health Laboratory Service, UK (2002) the number of heterosexually acquired HIV infections diagnosed in the UK has risen significantly since 1985. The increase since 1996 has been particularly noticeable. As a result, since 1999 there have been more diagnoses of heterosexually acquired infection than of infections acquired through sex between men. Most of those diagnosed in the UK who have acquired infection heterosexually were not infected in this country. Over 80% are recorded as having acquired infection abroad. Of these, only seven percent were infected by a "high risk" partner (a bisexual man, an injecting drug user, or someone infected through blood transfusion). With the increase in the figures of those who acquired their infections heterosexually there has been an increase in the numbers of women diagnosed.

Although drug use among women in India appears to be quite uncommon and there is no clear evidence that this situation is changing (UNAIDS-UNDCP 2000), drug use is a significant factor in the spread of HIV in Edinburgh (Robertson 1990). According to Thomas (1990) Edinburgh had the unenviable position of having the highest proportion of sero-positive injecting drug users in Britain. Thus, Edinburgh has come to be known as the AIDS capital of Europe (Richardson and Gaskell 1989; Des Jarlais and Case 1992).

While the exact reasons for the rapid spread in Edinburgh is not fully ascertained, the two most important factors that may have contributed to the rapid spread in the past are a lack of HIV/AIDS awareness amongst injectors and a perception among injecting drug users that HIV/AIDS was not a threat. These individuals were therefore unlikely to practice risk reduction behaviour. Injecting equipment might have been shared because of a limited availability or on account of friendship rituals (Stimpson et al. 1998). Moreover, highly efficient mixing patterns within the drug injecting population also facilitated the rapid spread. Often dealers kept a set of injecting 'works' which were regularly lent out to their customers, who generally wanted to inject themselves as soon as they procured the drug (Aggleton et al 1989; Sims and Moss 1991; Des Jarlais and Case 1992; Whitehead 1996). By 1985, 50 percent of the injecting drug users were infected, one third of who were women (Robertson et al. 1986). According to the Lothian Health Board (1988), by 1987, not only did Edinburgh have 30 per cent of all women in the UK known to be infected with HIV, but Edinburgh also had the highest prevalence of HIV infection of

anywhere in the UK. Research studies show that there has been a decrease in sharing injecting equipment in Edinburgh (Robertson et al. 1988; Morrison 1991; Green and McCreaner 1996) with the introduction of harm minimisation strategies and a large expansion in hypodermic needle exchange schemes (Brettle 1991; King 1993).

## **History of the HIV/AIDS Epidemic**

HIV/AIDS came at a time of increasing complacency about infectious diseases. The 20th century had seen rapid and significant advances in the field of medicine; widespread success had been achieved with antibiotics and vaccines. These strides had substantially benefited humanity, although admittedly not all of it. Most of the great epidemics of the past, such as smallpox, typhoid, leprosy, tuberculosis, and bubonic plague, were curable, especially in industrialised nations, and held little terror. The perplexities of cancer were being unraveled too. It was against this backdrop that a sub-microscopic entity, the virus causing AIDS, emerged (Hancock and Carrim 1986). Mann (1988) argues that HIV was insidiously creeping up on the world for at least a decade before it was noticed in 1981, when it became the single most important health problem to confront society.

AIDS is a condition that was first officially recognised in the United States in 1981, when doctors noticed an increased frequency of 'pneumocystis pneumonia' and a rare cancer—'Kaposi's Sarcoma'. Patients were dying because their immune systems were unable to fight these diseases or any other common illnesses. All patients were young homosexual men. This prompted the emerging syndrome to be dubbed Gay Related Immune Deficiency (GRID) and the 'gay plague'. It was not until 1983 that the name was changed to Acquired Immune Deficiency Syndrome (AIDS). This was both because gay activists objected to the social implications of the term GRID, and, because researchers realised the inaccuracy of the term. AIDS was affecting gay men, but it also infected injecting drug users, their sexual partners and children, as well as recipients of blood transfusions and blood products (Bayer and Kirp 1992; Squire 1993). Within a span of two years after CDC's first report, AIDS had appeared in countries throughout the world. It was described in Africa soon after its 1981 description in the USA (Clumeck et al. 1984). It was only in 1984—three years after the first cases of AIDS were reported by the CDC in the United States—that the HIV was identified. Most experts believe that the human immunodeficiency virus, or HIV, causes AIDS. There are two known variants of HIV: HIV-1 and HIV-2. Both of these cause AIDS, but the former is thought to be more globally prevalent and virulent and may lead to AIDS more rapidly (Ewald 1994). HIV-2 is most often found in West Africa, though sporadic cases have been observed in the Americas, India and a few European countries (Mann et al. 1992).

Some scientists believe that HIV/AIDS may have been present in the world for almost a century. Intrigued physicians in the past documented AIDS-like conditions in medical journals and saved frozen samples of blood and infected tissues from patients whose symptoms match the modern-day syndrome of AIDS for future medical advances to resolve. These unfrozen samples yield evidence without a doubt



that HIV, the putative agent of AIDS, was present in these samples (Root-Bernstein 1993).

## **HIV/AIDS in India and the UK**

India provides a lens through which issues of development and women in the HIV/AIDS epidemic can be viewed. HIV was first detected in six sex workers living in Madras in 1986 (Pais 1996; Ramalingaswamy 1992), which was five years after the disease had first revealed itself in the United States. It was not until the early part of the 1990s that India showed up on any international health indicator as a threatened country (Burns 1996). At the start of the Indian epidemic the general impression was that the virus had a very low prevalence in the country and would be of little consequence to the health of its citizens (Pais 1996).

For a long time, Indians, irrespective of their class, caste, ethnic, or cultural background, believed that their deep-seated family traditions, social conservatism, and spirituality would protect them from the harms of this global epidemic (McDonald 1992). They considered themselves to be a sexually conservative society, unlike other promiscuous cultures of the developed nations of the world. These theories allowed the Indian government to play down the problem of the HIV epidemic. But the considerable socio-economic growth that was occurring in India, along with the increase in migration from small villages to urban cities, began to change traditional values and practices. When the spread of HIV first became evident, many, especially those in government positions, believed that the virus was being brought into the country by foreign tourists and students (Pais 1996). The government had established a plan that would deport any non-Indian citizen who tested HIV positive (Pais 1996). As the infection continued to expand, however, government officials began to realise that these policies were failing to end the spread of the disease and they were then nullified. Pais (1996) argues that the Indian government chose to turn its head away from the growing number of individuals dying from the disease. It is interesting that it was not very different in the United States, where also, at the time of the initial outbreak, no one in the government wanted to make an issue of what many believed were social deviants. The high-risk groups in India were similarly stereotyped as being deserving of their disease because of their promiscuous behaviour.

By 1990 the virus was becoming evident even in the most rural of areas (Pais 1996). These rapid changes indicated that HIV infection was quickly becoming a national crisis. Finally, in October of 1992, the Indian government established the National AIDS Control Organisation (NACO) and announced a hundred million dollars (85 million dollars of which was a loan from the World Bank), five-year programme which would go towards a national AIDS control system (Burns 1996; Imam 1992; McDonald 1992; Pais 1996).

The AIDS epidemic in Europe and in Britain seems to have emerged in waves. The first wave being gay men, followed by the second of injecting drug users, where the ratio of HIV-infected men to women was three to one. The third wave of the

epidemic appears to be cases resulting from heterosexual transmission, which involves women more than men (Bury 1992). Bury suggests that in the United Kingdom, the majority of adults with AIDS up to the end of 1991 were men. Women only contributed five per cent. In Scotland the figures were higher: at 12 per cent, compared to the UK as a whole. The major mode of transmission in Scotland has been injecting drug use, although in the beginning of the epidemic it seemed to have only a few cases of HIV in gay men, with no evidence of an indigenous sexual spread until 1983.

McRae (1989) argues that the incidence of HIV/AIDS in Edinburgh followed a radically different pattern from the rest of the UK, because it spread most rapidly among drug users. More than half those infected with HIV in Scotland acquired it through injecting drugs (Hepburn 1992). In Edinburgh, the early 1980s experienced an explosion in the numbers of young people who used drugs (Stimson 1987). In 1982, following a shortage of marijuana, heroin became the fashion drug. By early 1984, police realized that heroin use was out of control, so they instigated a crackdown on drug paraphernalia, confiscating the needles that addicts used to inject themselves (Shilts 1989). In Edinburgh, running parallel with this drug culture was the onset of HIV/AIDS. HIV was transmitted through the sharing of contaminated needles, in addition to other means. A concatenation of factors, such as increasingly young people injecting drugs for the first time, unavailability of needles and syringes, along with the popularity of shooting galleries or friendship rituals (Robertson 1990) forced addicts to share needles and provoked the rapid spread of HIV (Robertson 1990). Edinburgh's HIV/AIDS infected drug using population was concentrated on large decaying council estates that were situated on the periphery of the city in areas characterised by multiple deprivation (McRae 1989; Brettle 1995).

## **Medical Advances in HIV/AIDS Treatment**

Since the inception of the HIV/AIDS epidemic, considerable progress has been made in treatment of the disease. Although there is still no way to cure HIV infection or fully prevent the onset of AIDS, a regimen of treatment has been developed that can delay the onset of AIDS and allow infected persons to lead healthy lives for longer periods.

HAART (Highly Active Anti-Retroviral Therapy) consists of multiple anti-HIV drugs that are prescribed to HIV-positive people, even before they develop symptoms of AIDS, without considering that many will never develop the symptoms. The therapy usually includes a combination of drugs: one nucleoside analog (DNA chain terminator), one protease inhibitor and either a second nucleoside analog ("nuke") or a non-nucleoside reverse transcription inhibitor (NNRTI), and is therefore commonly known as Combination Therapy.

These drugs are very expensive and have not been available to the majority in the third world who are poor. Despite the significant medical advancements and progress



in prevention technology by the end of the year 2001, the large majority of over 38 million people living with HIV/AIDS in low and low-middle income countries “remained severely deprived of even basic medications for treating HIV-related illnesses and for relieving pain” (UNAIDS 2002b, p.142). My respondents in Edinburgh were all in a position to take advantage of these therapeutic advances, because the government paid for their treatment. Most of them had either been or were considering HAART. However, for my respondents in Bombay treatment remained a distant hope.

Gallant (2002) suggests that the unparalleled benefits resulting from HAART have been well described in the medical literature and the lay press. Therapeutic options for people in the developed countries of the world continue to expand with the development of new drugs and new strategies for using them. Moreover, he points out that treatment becoming easier for the patient, with more satisfactory regimens with low pill burdens. However, he argues that drug resistance and failure of treatment are still common experiences; and that the management of ‘treatment-experienced patients’ has become ever more complex, both because of expanding choices for therapy, and because of the necessity to be able to understand and interpret the test results of drug resistance.

Recent developments have brought new hope that treatment will become more available in India. The Indian pharmaceutical manufacturer CIPLA (Subbu 2001) has agreed to provide the cocktail drugs (three drugs including reverse transcriptase and protease inhibitors) at cost price to the government of India. However, despite CIPLA's offer there are several issues related to the implementation of HAART in India. Political will is a crucial variable, which is outside the scope of this present research, but all the same remains a crucial issue in the likelihood of treatment reaching the masses of positive persons in India.

The real hope is to be able to prevent the transmission of HIV, through existing technology, such as male and female condoms, clean syringes and mandatory testing of all blood and blood products; and through future technologies, such as, vaccines and microbicides (a form of ‘chemical condom’ that prevents bacterial and viral sexually transmitted infections).

The complexities of the HIV make vaccine development challenging and elusive. After years of pessimism and setbacks, the new influx of money from government and non-government sources has created a number of very large and international collaborations that are involved in the search and creation of a vaccine (Cohen 2002; UNAIDS 2002c). Although there is no definite blueprint for controlling the epidemic, the past twenty years have witnessed the growth of tools and knowledge that can result in success: “the world now has a road map for the fight against AIDS” (UNAIDS 2002c; p.20).

## APPENDIX B

### INTERVIEW GUIDE

#### **"Living with HIV/AIDS: Experiences, Transitions, Turning Points and Transformations in the Lives of Women from Bombay and Edinburgh"**

The subject of my research is "Living with HIV/AIDS: Experiences, Turning Points, Transitions and Transformations in the Lives of Women". The purpose of this study as the title suggests is to develop a deeper understanding of the life experiences, 'turning points', transitions and transformations or changes in the lives of women after they received a positive diagnosis.

To make this study possible I have been meeting and sharing the stories of positive women in Edinburgh and Bombay. Today, I am requesting you to share your account and life experiences with me through an interview.

During the interview I will be asking you to share your experiences, thoughts and feelings, which I will be, tape recording. The interview will last for approximately two to two and half-hours. If at any point during the interview you need to stop or ask me something, please do. If there is any question you feel you may not want to answer, please do feel free to tell me. I would like to reassure you once again that your identity will at all times be protected.

Before we start the interview, I want to thank you for making this study possible by your willingness to share many personal aspects of your life with me. I am also really grateful for the time and effort you have agreed to give me.

At the end of the study I hope that the experiences you and other women have shared with me, become testimonies to the ability of positive women to live with the virus.

Is there anything that you would like to ask me before we start with the interview?

#### **Questions for the Study:**

*The matter in brackets to be used as prompts. Sub-questions are marked with a bullet point.*

#### **I Description of the Sample: Personal Background Data**

1. Would you like to start by telling me a little about yourself?
  - What is your name?
  - What is your age?

- What is your nationality?
- Have you had any formal training after school? What have you done?
- Could you give me your address and tel. no: in case I need to contact you again [also to send a letter of thanks]
- How long have you lived at this address?
- Do you own this place, or is it a rented accommodation? [Any other? what sort?]
- May I ask you whom you live with?
- Are you married or in a long-term relationship?
- Do you have children?
- How old are they?
- Are they studying? Or what are they doing?
- Who supports them financially?
- Are you presently employed? [If yes] What do you do? How long have you been working in this job?
- [If not] have you worked before? [If yes] What did you do? Could you tell me under what circumstances you discontinued your work?

## **II Before Diagnosis**

1. I would now like to talk to you about the time before you were diagnosed. Would you like to tell me a little bit about your life just before you first noticed you might have a problem with your health? Or just before you were tested?
  - What year was this? How old were you?
  - Can you share something (memories, feelings, thoughts) that was important to you at that point in your life?

*[This question is aimed at encouraging the respondent to portray a picture of her life before she discovered that she was tested and diagnosed positive. It aims to take the respondent to the beginning of her story of living with HIV/AIDS]*

2. What else was happening in your life at this time?

*[If Question 1 is answered fully, I may not need to use this question]*

## **III Diagnosis**

1. What made you decide to get tested?
  - Which year was this?
2. What were you experiencing at the time when you decided to get tested?

- Can you share an important memory at the point of being tested?
3. Were you emotionally and mentally prepared for taking the test? Could you tell me a little more about your thoughts and feelings about being tested?
  4. Some of the women I have spoken to describe the process of diagnosis as a very painful and difficult period of their lives. May we talk about your experience when you first received a positive diagnosis?
    - How did you find out that you had tested positive? Who told you?
    - What were your reactions to the diagnosis? [Explore whether the respondent experienced the stages of grief: isolation, anger, bargaining, depression and acceptance]
    - Can you share an important memory or what you were experiencing at the point you found out that you were positive?
  5. Who did you share the results of your test with?
    - What was their response?
  6. Who supported you through this period of your life?
    - Did you feel the need of any other support?
  7. Were you in a relationship or married when you received a positive diagnosis?
  8. In what way did it affect your relationship with your partner?
  9. Communication and sharing: did you become closer? Or more distant?  
[Pattern: positive / negative; sharing: at the levels of emotions, physically]
  10. Do you think that discovering that you were positive was a turning point in your life? By turning point I mean, did your life take a new direction from that time onwards?
    - Can you tell me in what way it changed your life?
    - Was there a time when you felt life would never be the same again?
    - At this point what were your thoughts about your future?
  11. Finally, my last question about the time of your diagnosis: can you share any memory of something that was really important to you at the point of diagnosis. It could be a very happy joyful memory or it could be something less happy, a pain or a loss, or it could be both or any other memory that you would like to share.

12. The next question is a more personal one. Would you please share with me how you think you became positive?

#### IV Since the Diagnosis

You have been sharing very personal and at times painful parts of your life story with me. I am really grateful to you for this. May we now talk about your life experiences since you were diagnosed? There are four aspects of your life, which I would like to talk to you about. You said you were diagnosed in 19--? So, it's been -- years since you first received your diagnosis?

1. Firstly, may we talk about your physical experiences since diagnosis?
  - Has your illness progressed since diagnosis?
  - Which year did this happen?
  - Have you experienced any physical symptoms of the illness? If yes, could you tell me something about your problems?

*[Side effects of medication? Withdrawal symptoms: for those respondents who have spoken about their use of drugs]*

2. What kind of medical treatment have you undertaken since diagnosis?
  - Have you used alternative medicine?
  - Did the treatment help you? In what way?
3. Are you on combination therapy? [Or, you said that you are on combination therapy]
  - When did you start taking combination therapy?
  - Has it helped you? In what way? Or, in what way has it been unhelpful?
  - Would you say that this treatment has changed your life? Could you please share with me how?
4. How has the disclosure of your diagnosis affected your relationship with your family and children?
5. How has it affected your decisions about becoming pregnant and having children?
6. I would like to talk to you about some of the social aspects of living with HIV. Some people have said that HIV cuts them off and makes them feel very alone. Has this been your experience?
7. Since you were first diagnosed have you shared your positive status with other people? Who were these people? Would you please share some of the

positive and negative social experiences you have faced in your relationships with people after diagnosis?

8. I would now like to ask you to share some personal aspects about yourself or you as a person. In what way has "being positive" affected or changed the way you feel about important aspects of your life:
  - Yourself? (Your life?)
  - Love?
  - Religion or faith?
  - Pain and loss? (Death?)
9. I asked you earlier, whether the point when you discovered you were positive was a major turning point in your life and you said, that it was (or, you said that you did not think that it was). Would you say that since diagnosis you have experienced a turning point/ or another turning point in your life? Can you share something more about it?

## V      Looking Ahead

1. Do you feel differently about your life today?
  - In what way? [If yes]
2. It is generally said that most experiences in life help us to learn something, and thereby help us to grow from them. Do you view this true of your experience of HIV/AIDS? If yes, please share with me what you feel you have learnt and how you feel you have grown? If not, tell me some of the reasons why you think that is?  
  
*[Developed inner strength or potential she did not know she had?]*
3. May I ask you to share with me some of your hopes and dreams for your life now and in the future?
4. Finally, may I ask you about your experiences in relation to testing and services? Is there any guidance you can give or any suggestions you can make which would be useful for both positive women and professionals?
  - In what way were you were prepared for testing?
  - Did you feel that you had enough information about testing?
  - What kind of information did you receive?
  - What kind of support do you think women who are to be tested need?
  - What support have you received since testing?
  - Do you feel this support has been adequate? In what way has it been or not been?



- What kinds of support do positive women need?

At the end of the interview I will ask them if there were anything they would like to ask me? Or, if there is anything else I should have asked them and thank them.

## APPENDIX C (I)

### *REQUEST TO PARTICIPATE (ARCON, BOMBAY)*

***Dina P. Sidhva***

Dear

I am studying for a Ph.D. in the Department of Social Work at the University of Edinburgh, Scotland. The subject of my research is 'Living with HIV/AIDS: Experiences, Transitions and Turning Points in the Lives of Women'.

The purpose of my study is to develop a deeper understanding of the life experiences and the change that women undergo when they are diagnosed as positive. To make this possible I am requesting you to share your life story with me through an interview. I will also be speaking with women in Edinburgh. Sharing the life stories of women in Bombay and Edinburgh will help to gain a greater awareness and understanding of women's experiences of HIV/AIDS in different parts of the world.

You may wonder why this study is important. It is important because through this study your voices as an individual woman living with HIV/AIDS and, collectively as women living with HIV/AIDS will provide insight and a deeper understanding of the experience of living with HIV/AIDS. By sharing your life story you will help to provide hope and support to other positive women, their families, friends, professionals and other interested persons who read it in your own 'words'.

The Interview will consist of one session, which will last approximately two to two, and half-hours. During the interview questions will be asked regarding your experiences and feelings as an HIV positive woman. The interview session will be tape recorded to ensure a more accurate and complete data collection. These tapes will not be shared with any other individuals. Information contained in the transcripts will be anonymously discussed with my academic tutors and the staff at ARCON for academic and therapeutic purposes respectively. The final report, containing anonymous quotations, will be available to all at the end of the study.

I invite and thank you for sharing your life stories of living with HIV/AIDS with me.

Sincerely

DPS

## APPENDIX C (II)

### REQUEST TO PARTICIPATE (SOLAS, EDINBURGH)

***Dina P. Sidhva***

Dear

I am studying for a Ph.D. in the Department of Social Work at the University of Edinburgh, Scotland. The subject of my research is 'Living with HIV/AIDS: Experiences, Transitions and Turning Points in the Lives of Women'.

The purpose of my study is to develop a deeper understanding of the life experiences and the change that women undergo when they are diagnosed as positive. To make this possible I am requesting you to share your life story with me through an interview. I have already spoken to women in Bombay. Sharing the life stories of women in Edinburgh and Bombay will help me to gain a greater awareness and understanding of women's experiences of HIV/AIDS in different parts of the world.

You may wonder why this study is important. It is important because through this study your voices as an individual woman living with HIV/AIDS and, collectively as women living with HIV/AIDS will provide insight and a deeper understanding of the experience of living with HIV/AIDS. By sharing your life story you will help to provide hope and support to other positive women, their families, friends, professionals and other interested persons who read it in your own 'words'.

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I invite and thank you for sharing your life stories of living with HIV/AIDS with me.

Sincerely

DPS

## APPENDIX D (I)

### *LETTER OF INFORMED CONSENT (BOMBAY)*

THIS IS TO CERTIFY THAT I, (Print name) HEREBY agree to participate as volunteer in the above named research. I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the tapes will not be made available to anyone other than the researcher. I understand that the information contained in the transcripts will be anonymously discussed with your academic tutors and the staff at ARCON for academic and therapeutic purposes respectively. I understand that the information may be published, but my name and specific identifiers will not be associated with the research.

I understand that I am free to deny answering any specific question I choose to during the interview. I have been given the opportunity of asking any questions and clarifying any doubts. All such questions and doubts have been answered to my satisfaction.

Signature of Respondent

Date

## APPENDIX D (II)

### *LETTER OF INFORMED CONSENT (EDINBURGH)*

THIS IS TO CERTIFY THAT I, \_\_\_\_\_ (Print name) HEREBY agree to participate as volunteer in the above named research. I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that the tapes will not be made available to anyone other than the researcher. I understand that the information contained in the transcripts will be anonymously discussed with your academic tutors for academic purposes only. I understand that the information may be published, but my name and specific identifiers will not be associated with the research.

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Signature of Respondent

Date